

**An ethnographic study of
cardiovascular disease prevention:
the social organisation of measures, knowledge,
interventions and tensions in English general practice**

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Abstract

This thesis is about different ways of knowing about people's health, and about what happens when these different knowledges intersect at the frontline of general practice — when people (patients) consult with healthcare professionals. Starting with the accounts of patients, I use institutional ethnography (Smith, 2005b) to explore how patients' (and healthcare professionals') knowledge and practices are socially organised.

Within healthcare services, policymakers are coordinating activities to prevent cardiovascular disease, based on knowledge of population health from vast epidemiological datasets such as the Global Burden of Disease project. A suite of 'lifestyle' and pharmaceutical interventions are promoted by policymakers as evidence-based approaches to preventing cardiovascular disease (including heart attacks and strokes) within the population. The flagship Health Check programme aims to prompt people to make changes to their diet and exercise habits, and identify some who will benefit from additional interventions to reduce their risk.

However, interviews with patients, observation of preventive care in practice, and the concerns of some general practitioners suggest that cardiovascular disease prevention is not as simple or unproblematic as it first appears; patients' knowledge of their own health needs is often at odds with the preventive care provided. I show how patients look for a discussion with healthcare professionals about how they can best implement preventive approaches, but find that they are given standardised 'automated' responses which do not take account of their own individual circumstances or preferences.

Despite prominent notions of 'shared decision-making' and patient involvement written into clinical guidelines, and despite healthcare professionals striving to provide 'patient centred care', tensions persist between an institutional knowledge of prevention and a local, experienced knowledge of what is required to improve health. This thesis explores these tensions, their impact, and how both HCPs' and patients' activities are coordinated remotely from the frontline of general practice.

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Abbreviations

BMI	Body mass index
CCG	Clinical commissioning group
CVD	Cardiovascular disease
EBM	Evidence based medicine
GBD	Global burden of disease
GP	General practitioner
HCP	Healthcare professional
IE	Institutional ethnography
LA	Local authority
NCVIN	National Cardiovascular Intelligence Network
NHS	National Health Service
POD	Preventing Overdiagnosis
SDM	Shared decision-making
T2DM	Type 2 diabetes mellitus

Chapter 1 An introduction: starting from experience

“He is a better physician that keeps diseases off us, than he that cures them being on us. Prevention is so much better than healing, because it saves the labour of being sick.”

(Adams, 1618, p.572)

The adage ‘prevention is better than cure’, as referenced in the above excerpt from a 17th century sermon, has been established in English culture for centuries (Speake, 2015). The mantra is so thoroughly ingrained that to question it feels ridiculous. Yet questioning it is what this thesis does. However, this is not *abstract* questioning — philosophising on ‘prevention’ as an idea. This thesis is about how ‘prevention’ is *practised* in English primary healthcare (general practice) and the issues that arise for patients as they are drawn into these preventive practices.

This is an institutional ethnographic study (Smith, 2005b), which explores the prevention of cardiovascular disease (CVD), “the number 1 cause of death globally” (World Health Organisation, 2017b). CVD prevention turned out to be more contentious than it might at first appear. Although policymakers, frontline healthcare professionals, and patients all frequently referenced the idea that ‘prevention is better than cure’, I discovered that many also referred to troubling experiences relating to preventive practices. Some frontline healthcare professionals (HCPs) in particular explicitly challenged the idea that these practices were “[saving] the labour of being sick” (Adams, 1618, p.572). On the contrary, they argued that these practices were creating new work for patients, with limited assurance of future benefit.

This thesis investigates and redefines these concerns from a patient standpoint. ‘Dan’s story’ (below), taken from my data, provides a point of departure for the analysis undertaken in the subsequent chapters. His experience, filled with the details and particulars of his life, holds traces of many of the institutional relations that organise contemporary approaches to addressing the problem of CVD. Dan’s unique set of experiences happened within a complex of scientific disciplines that inform local, national and international CVD prevention initiatives. His actions to improve his health (or not) have broad consequences relating to his use of healthcare services.

For the purposes of this analytical approach (institutional ethnography — see 1.2 and 3.2), it is important to foreground that health centres are organised within a funding structure and payment systems. Additionally, Dan's health practices, including those which are specifically known at his health centre as 'CVD prevention', link him into national and international guidelines, policy reports, the pharmaceutical industry and so forth. Key features of institutional relations, some of which I take up in more detail throughout this analysis, are outlined in Chapter 2.

1.1 Dan's story

This study starts with “the actualities of people's everyday lives and experiences” (Smith, 2005b, p.10). Below, I present one individual's experience of preventive care through his local health centre, and chronicle how this care intersected with his own efforts to improve his health. It is a summary of my conversation with Dan as orientation for the chapters which follow.¹

¹ Dan has seen a draft of this chapter, confirmed that he is satisfied with my representation of his account, and was keen that I share his story.

Dan is in his late 60s. He used to work as a long-distance lorry driver which involved heavy lifting, long periods of sitting, and a diet which he describes as "keeping the body fuelled for work", "eating badly". In his 40s, he developed high blood pressure and an underactive thyroid for which he started treatment (two different blood pressure medications and thyroxine) and his GP also prescribed a statin (to treat a high cholesterol measurement).

Six years ago, he had an accident which required extensive hospital treatment and resulted in him being unable to work. This made him start to think afresh about his health, and his weight in particular. After recovering, but experiencing some more minor health issues, a GP suggested "why not try a lifestyle change?" So four years ago, Dan resolved to make significant changes. He put himself "in task mode", reading extensively about different approaches to healthy living, and working out what he was able to do in light of his physical limitations. He started a new diet ("plenty of fruit, vegetables with positive nutrients [...] kale and spinach [...] no fried food, pies"), and new exercise regime (walking and swimming). Now, having lost approx. 20kg, he tells me that his "lifestyle is good" and he is very "conscientious" — he drinks very limited alcohol, and doesn't smoke. Dan also enjoys meeting friends at the pool, and goes out for a drink every couple of weeks. Having been "very unknowledgeable" about his health in the past, Dan tells me "because I do a lot of study and research and whatever, I know more or less how my body works". He has transformed himself into what is sometimes in the research community called an 'activated' patient or, in the clinical community, a 'motivated patient'.

Despite having started new lifestyle habits, Dan developed "blackouts", "heart rhythm fluctuations" and "atrial fibrillation" and was "going in and out of hospital". Then two years ago, he came to connect these symptoms with the long-term side-effects of taking blood pressure medication (a diuretic). This was suggested by a hospital doctor, and corroborated by doing online research. In response to his health problems and his belief that some of these were likely to have been caused by (preventive) medications, he "knocked [the diuretic and statin medications] on the head", and also declined a prescription for a "blood thinning" medication to treat atrial fibrillation, describing it as "toxic" because of the likelihood that it would

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cause easy-bruising and other side-effects. He decided to rely on his ongoing lifestyle change to compensate for the declined medication.

Dan's GP tried to persuade Dan against coming off the medications by providing information on research studies which demonstrated that these were important in preventing heart attacks and strokes. However, Dan says they did not apply to him because they related to "population factors as regards lifestyles [which he did not have]". Dan reports that his GP "was always, you know, 'you need this, you need that, you need the other', and I am thinking 'well hang on a minute, I don't really need them'." The conversation came to a head when "[the GP] got very, very vociferous and 'you know you will have to', [...] the word that comes to mind is belligerent, he was very adamant to the point of raising his voice. [...] There was no meaningful conversation between the two parties. It was 'you will', 'you must'". Dan tells me that he responded with "I won't" and ended the consultation with "thank you doctor, I am gone, and I walked out". As a result of the argument, Dan has now told the health centre that he no longer wants to see this particular GP.

Dan finds other GPs to be less pushy with him, but they repeatedly try to tell him that he should be on preventive medications. "I always feel under pressure, because they look at my notes and they will go down and see 'oh yes you should have been on these, you should have been on those'". "To put it bluntly, I feel that the doctors think that they have the right to insist that they are right, rather than listen to the patient. I am not saying all doctors are like that, but most of them". As a consequence, Dan minimises contact with GPs, often choosing telephone rather than face-to-face consultations, and not attempting to see the same GP regularly — he tells me that the GP, not knowing him well, then usually focuses only on the issue about which he is consulting, and does not consider his health more broadly. A little while previously, he had been reluctant to go to the GP with an infection and had ended up being hospitalised.

Dan is not blasé about his health, however, and still worries about whether his blood pressure and cholesterol are OK. His blood pressure still sometimes runs a bit high, his cholesterol is slightly higher than what is considered 'normal', and he tells me that, although he no longer has atrial fibrillation, that he knows medically that "the long lasting effect is always going to be there because of the long time I was on [the

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diuretic medication]” — i.e. a heart abnormality. He understands that there may be benefits from the preventive medications the GP has proposed, but he also wants to avoid the side-effects of medications and has therefore decided to (as far as possible) manage his conditions through a better lifestyle. He still takes a blood pressure medication and thyroxine, and attends regular check-ups with the nurses (who he tells me are “lovely”), as prompted by the health centre’s administrative systems.

Dan swings between blaming himself for problems with the health centre (assuring me that he usually “[gets] on well with people”), and telling me that he feels “quite aggrieved” by what has happened. I press Dan about his response to the “vociferous” GP: surely he thought the medication was so important for his health that he just wanted to persuade him? Dan however will not accept my hypothesis. Instead, he puts his experiences down to GPs’ sense of self-importance. “To be told by a doctor that you need A, B, C and D, and I think ‘well hang on a minute why?’, I am always asking ‘why?’ and I think they don’t like that. They like to be thinking of themselves that they are up there with the greats”. He also speculates that his experiences are because GPs are influenced by pharmaceutical companies — “I told him ‘you know a doctor’s first priority is to look after the patient, not the medical companies’”. When asked to explain, he suggests “they have been told to push these drugs, by the big pharma companies, if they don’t push them they feel that you know they are not going to make their bonuses”. Dan had come to this conclusion from reading newspapers and research journals.

When I ask Dan about his general health priorities (is it to live as long as he can?), Dan tells me “yes, but with a codicil on that, that I want to be healthy”. He outlines what ‘being healthy’ means to him — “If my body is in sync I can [speed-walk 3 miles] 7 days a week, so therefore everything tells me that my body is working normally, and things are happy. And it is easy to get along [...] I am happy with my life and my body is happy and I can sleep well at night. And I wake up before the alarm, and I am up and out. And like this morning I beat the alarm by 5 minutes, so I was up and out of the house for 05.40. It was a lovely morning, the birdsong was beautiful so I did my 3 miles [walk], I came home, had breakfast, and you know all the things that you do, and so then I was swimming at lunchtime, and I got my lunch, did some ironing, and did the cleaning up. It’s all like, ‘well it’s been a good day.’

EX1 Dan’s story [a summary from interview]

Dan's story introduces the terrain of 'preventive care', and patients' prevention 'work'² — an empirical focus of this thesis. Here is one individual, Dan, living his life and interacting at various points with HCPs at his health centre. He originally attends his GP for ad-hoc care of symptomatic conditions, but soon these interactions lead to further activity known within healthcare as 'prevention'. 'Prevention' appears in both the *language* of future danger (when the GP invokes the possibility of a heart attack or a stroke) and as a set of related *practices* initiated by HCPs at the local health centre. These include HCPs' work to, for example: promote lifestyle change; opportunistically check blood pressure; provide regular check-ups to people with 'risk conditions' (e.g. high blood pressure, high cholesterol, and atrial fibrillation); and prescribe preventive medications for these conditions. (Definitions of CVD and its risk factors / conditions, along with key 'interventions' to address them, are outlined in Chapter 2.)

CVD prevention, as I show it here, is institutional work, coordinated by policymakers from outside the local general practice setting, and orchestrated locally by frontline HCPs. However, it is clear from Dan's account that the most basic work of improving health lies with patients themselves — although HCPs frequently bemoan patients' lack of commitment to this work. It is Dan who previously ate "badly" but now determines that he will get up and go for a 3-mile walk in the morning, and plans to source and finance fresh organic vegetables. Even preventive medications, although prescribed by his GP, are for him to swallow each day. Increasingly, national policy has focused on prevention as *collaborative* work between HCPs and patients; HCPs' work has been understood to involve techniques to 'engage' or 'motivate' patients, and patients' work involves taking responsibility for their own health and responding to the preventive opportunities provided through health services. In a similar vein, calls to end the 'paternalism' of HCPs, to shift away from a traditional medical model (in which HCPs' advice dominates consultation and patients are expected to 'follow it'), and enable patients to take greater responsibility for their own health

² Terms such as 'work', which have specific meanings in institutional ethnography, are defined later in this, and the following, chapters.

are ubiquitous in policy. The increasing use of behavioural interventions in general practice attests to the institutional importance of prompting patients to do more to look after their own health (see Chapter 4).

For now, however, I ask the reader to set aside preconceived ideas about what is involved in prevention — and the problems / solutions which relate to such activities. Dan’s account instead raises questions. In particular, we might wonder why, although he is successful at changing his lifestyle, his preference not to accept particular medical interventions is apparently so troublesome for the HCPs treating him? His resistance appears to be an ‘unauthorised’ form of involvement in his own health — which he called “going against the grain”. As a result, his relationships with at least some of the HCPs at his health centre were strained, and impacted other areas of his care. His recent reluctance to see a GP for a minor infection illustrates this impact; failure to treat the infection expeditiously led to an extended stay in hospital.

1.2 An ‘alternative’ sociology of knowledge: brief introduction to institutional ethnography

Dorothy Smith, founder of institutional ethnography (IE), has described the approach as an “alternative sociology” — “sociology *for* people” rather than sociology which follows conventional approaches “in which people [are] the objects [...], whose behaviour [is] to be explained” (Smith, 2005b, p.1). In line with this approach, I do not present Dan’s experience in order to examine his behaviour, or how he makes sense of his experiences. Dan’s experiences are in many ways unique to him, not to be generalised as ‘typical’. Instead, I use his story to point to tensions between different “**FORMS OF KNOWLEDGE**”³ — on the one hand, Dan’s knowledge of trying to improve his health, and on the other, an “externally derived and explicitly organised” system of ‘prevention’ (Rankin and Campbell, 2006, p.7). Glimpses of this institutional knowledge about CVD prevention can be seen in Dan’s story when his GP tells him that he should be taking particular preventive medications (“you need A, B, C or D”), or suggests a “lifestyle change”. This is an institutional “knowledge for taking action” (Rankin

³ Where I introduce key IE terms, I indicate by capitalising (see p.vi for index).

and Campbell, 2006, p.7) which Dan is initially willing (and perhaps keen) to accept, but which eventually starts to clash with his personal experiences of taking the medications, and his developing knowledge of the best ways to improve his own health. For some patients, they might find that these different ways of knowing are mutually reinforcing, but in Dan's case they create tension.

The '**PROBLEMATIC**' is a technical term in institutional ethnography, similar (but not equivalent) to a 'research question' (see Chapter 3). In Smith's words, "it directs attention to a possible set of questions that have yet to be posed or of puzzles that are not yet formulated as such, but are 'latent' in the actualities of our experienced worlds" (Smith, 1987, p.89). Dan's story provides a helpful illustration of a common feature of patients' accounts — of disappointing or frustrating interactions with HCPs, who seemed unwilling or unable to address their particular concerns about their prevention work, and with whom they failed to 'connect'. Although his case is characterised by confrontation between patient and HCPs, and might (superficially) be interpreted as a consequence of simple communication failures, I argue that these types of tensions are frequent, troublesome, and reflect more systemic problems with how 'prevention' comes into patients' lives.

Explicating the problematic in institutional ethnography involves studying people's '**WORK**' — in a very generous sense of the word which includes "anything that people do that takes time, effort and intent" (Smith, 2005b, p.229).⁴ In Dan's case, preventive care has prompted him to undertake his own health improvement work, such as changing his diet/exercise habits. He has also been drawn into more healthcare-focused 'prevention' work such as taking medications

⁴ It is important to note here that work includes, but is not limited to embodied physical activities which can be observed. For instance, thinking, or listening, or "people's practical consciousness emerging from their efforts" are examples of 'mental work' (Smith, 2006a; McCoy, 2006; Bisailon, 2012).

for hypertension.⁵ However, neither Dan's individual health improvement work, nor his more healthcare-focused prevention work, is the main orientation of this study. The purpose of this thesis is to highlight a *different* form of work into which patients are drawn when they experience preventive care. I start by thinking of this work as '**fitting work**'⁶ — the work into which patients' are drawn to try to fit institutional knowledge of prevention (and what it involves in practice) with their more general knowledge of improving their health. This institutional knowledge of prevention is of individual risk factors, risk conditions and algorithmic calculations of risk with an accompanying suite of 'interventions', which often (I will show) fail to fit well with the broader needs of individual patients.

I am specifically highlighting the situations in which preventive work is *troublesome* and therefore *does not easily fit*. The GP's recommendation that Dan take medications for atrial fibrillation precipitates all kinds of work for Dan, who was hesitant about taking them. For instance, he works as he tries to assess the benefits and potential side-effects of these medications, and as he attempts to communicate with the GP about his concerns. As I will go on to show, this work is particularly burdensome for patients whose practical knowledge of their everyday health more acutely clashes with institutional knowledge of prevention, or who lack support for this work. Sometimes they then look to find *supportive and ongoing relationships with HCPs in order to help them adjust prevention work to their lives*, but instead experience preventive care as being 'processed' — for instance, when HCPs give them standardised information or prescribe medications apparently with little attention to them as individuals. In this case, they are left to fit preventive activities to their lives alone. As another participant, Julia, contended, "there's no doctoring these days, they're just like, it's just like,

⁵ For the purposes of initial analysis, I loosely differentiated between what I called patients' 'prevention' work, and what I called their 'health improvement' work (or similar). Here, I am using 'health improvement' work here to include all Dan's activities which are geared towards improving his health — whether these are related to healthcare services or not. I use 'prevention' work more specifically to point to activities which are coordinated through his health centre and his interactions with healthcare professionals. Although these types of work could be seen as opposite sides of the same coin, it turns out in this study that they frequently conflicted.

⁶ The notion of 'fitting work' proved useful during the analytical write-up of this study, but was not utilised as a theoretical framework. I have borrowed it from Pols (2012) who explores the way in which carers and patients 'fit' digital technologies into their individual situations. My analysis of fitting work evolved as I formulated the 'problematic' for this study.

automated”. Such experiences appear very different to the ‘collaboration’ presented within institutional texts about prevention, and are discussed in more detail as this analysis develops.

Dan’s story highlights that fitting work may be particularly challenging when people’s ideas about ‘being healthy’ fundamentally clash with institutional practices of CVD prevention. His attention to improving his health is not primarily motivated by a concern to live for as long as possible (or preventing heart attack or stroke), but is about his immediate and *experienced* health — knowing his body to be functioning properly, being able to participate in activities that are important to him, and in finding pleasure in the day-to-day. His is very individual knowledge of his own body, and his immediate experience or concerns about medical intervention clash with an ‘automated’ or standardised knowledge relating to statistical probabilities of the likelihood of having a heart attack or stroke. Yet, in Dan’s case, he persists with trying to make prevention fit through, for example, reading medical journals, and frequently reviewing and justifying his past decisions.

The aim of this chapter however is not to conduct a detailed analysis of Dan’s account, but instead to orientate readers to the chapters that follow *through* the everyday concerns of people experiencing preventive care. In IE, this is called ‘taking a standpoint’. **‘STANDPOINT’** is a location within an institutional order “that provides a guiding perspective from which that order will be explored” — “with some issues, concerns, or problems that are real for people and that are situated in their relationships to an institutional order” (Smith, 2005b, p.32). Starting from a patient standpoint, and focusing on patients’ fitting work enables a different view of CVD prevention practices. It draws attention away from clinical and academic discussions about the utility of particular prevention practices (for instance the benefits (or perhaps harms) of particular medications, and from academic discussions of whether/how patients should take more responsibility for their health) and towards concerns which are ‘real’ to patients. It is important to underline here that taking a standpoint with patients does not equate to ‘taking a stand’ *against* frontline clinicians or anyone else involved in the provision or organisation of preventive care! Indeed, the IE approach specifically *resists* objectifying or blaming individuals or groups of people, and points instead to the

social organisation of their work which is carried out within powerful institutional relations. Although some of the data utilised in this analysis could precipitate some instinctive criticism of HCPs (in particular), it is worth foregrounding that the professional participants, who I interviewed and observed, all volunteered to participate, and all presented as highly competent in their roles.

In the following chapters, I move beyond the local circumstances of patient / HCP consultations in general practice to explore the ‘social relations’ which shape these circumstances (see Chapter 3 for more detail on social relations) — and how these social relations are organised. In IE, ‘**SOCIAL ORGANISATION**’⁷ is a term used to describe the ways in which people’s activities (and knowledge of what to do) are coordinated away from their local setting. These forms of coordination are “reproduced again and again” across different times and places (Smith, 2005b, p.227) often through textual technologies which allow particular forms of knowledge to be standardised and spread from one location to another. I discovered in carrying out this study that the practices of CVD prevention were extensively shaped by such textual technologies, which enabled “objectified forms of organisation and consciousness” to coordinate people’s everyday lives (Smith, 2005b, p.18). Some of these might be apparent to those working in frontline clinical practice (e.g. the clinical guidelines, policies and so forth). However other aspects of the social organisation of CVD prevention will be less obvious both to patients and to frontline healthcare professionals — it is on these that I particularly focus this study.

This thesis is for people like two of my informants (Dan and Julia) and for the many other people who have concluded that troublesome experiences are because HCPs are asserting their importance, are badly trained, do not have time, or are receiving bonuses from a pharmaceutical company — or sometimes that they themselves are incapable or unmotivated to do what they ‘should’ be doing. I argue that, although there may be grains of truth in these and other explanations, they do not adequately account for the problems patients face when coming into contact with the practices of preventive care. This study is also for

⁷ Social organisation is closely related to other IE terms such as ‘ruling’, ‘social’ or ‘institutional’ relations.

stakeholders in the planning and delivery of preventive care — to expose the hidden work involved when CVD prevention, a socially organised set of activities initiated by HCPs, intersects with patients' lives and concerns about their health, and to point to potential opportunities for improvement.

1.3 Overview of chapters

Conducting an institutional ethnography is like following a trail from the everyday world into a “range of mountains” that represent a “complex of social relations” (Griffith and Smith, 2014b, p.8). My exploration follows various different trails, leaving many others only partially or unexplored along the way.

Chapter 2 helicopters the reader straight to an overview of the complex of social relations including epidemiological research about CVD and calculations of the ‘burden of disease’ within populations. It provides a brief overview of the destination to which the subsequent chapters will guide us. It spotlights the Global Burden of Disease (GBD) study and provides some clues about how this reaches into English policymaking about CVD prevention. This is just a flyover, however; we do not land to discover the local research (and other) practices by which these relations are coordinated.

Chapter 3 discusses the origins of this study and, in particular, the conversations circulating in policy and frontline practice relating to ‘evidence-based medicine’, ‘too much medicine’ and ‘shared decision-making’; these conversations are an important backdrop to the study, and appear in many guises throughout. I then extend the overview of IE begun in this chapter, and detail how I applied the IE method of enquiry by outlining the practical methods employed in this study.

Chapter 4 considers the suite of risk management interventions which are active in frontline clinical practice, and provides an introduction to the many preventive activities and textual technologies which crop up later in this analysis. I focus on a dominant risk management discourse (which I show as an ‘interventional arm’ of the GBD discourse discussed in Chapter 2). Within this discourse, interventions are often positioned as unequivocally beneficial to particular groups of patients. However, I also highlight the many uncertainties (and debates) about the scientific ‘evidence’ behind these interventions.

Chapter 5 provides a situated introduction to the everyday experience of one individual, Naomi, living in a deprived area of England. The analysis begins to highlight, empirically, how various interventions to support her with 'lifestyle' changes play out in Naomi's everyday life, and how she adopts a characterisation of herself as 'unmotivated'. Through insights from an informant delivering 'lifestyle interventions', and from HCPs working in frontline clinical practice, I reveal what 'motivating' patients involves and outline the range of lifestyle interventions which are positioned as good preventive options for patients like Naomi. The analysis reveals how standardised solutions to lifestyle compound Naomi's feelings of isolation, and lack of support. This analysis of Naomi's work gestures to the structures of 'health' and 'social' provision (and the allocation of resources) that undermine other potential sources of support within the local community (that struggle with minimal resources as they do not align with the types of standardised, 'evidence based' intervention used in authoritative knowledge about preventing disease). I develop the problematic sketched earlier in this chapter, and show the resonance of this emerging problematic with Annemarie Mol's analyses of good (and bad) care practices.

Chapters 6 and 7 move to an ethnographic exploration of the NHS Health Check — a flagship programme for CVD prevention. I base Chapter 6 on a 'walk through' of the main Health Check appointment in which I show HCPs systematically disengaging from offering the types of support patients frequently seek. I show how the programme's textual sequence organises HCPs to prioritise very specific aspects of patients' lives and bodies for intervention. Chapter 7 follows the Health Check process through to the 'follow-up' appointment. I highlight the use of risk scoring algorithms which calculate an individual's 'overall risk' of CVD, and particularly focus on how decisions about statin medications are made following a high risk score. I show HCPs working to persuade patients of the benefits of preventive medications — an approach which sometimes clashes with patients' efforts to discover whether, or how, preventive medications can 'make sense' in the context of everyday life.

In Chapter 8, I focus on the work of a group of GPs who make particular efforts to 'practise differently' (I call them 'activists'). Arguing against 'guideline-driven' care (which they understand to be typical of current contemporary clinical

practice), and the ‘medicalisation’ of clinical practice, they are attempting to adopt more ‘patient-centred’ practices. Through an analysis of their work, I show the challenges they face when trying to practise in a way that is genuinely responsive and instrumental to their patients’ overall health and wellbeing. I show that these challenges are a feature of the social organisation of prevention practices. This chapter extends beyond the frontline work of HCPs to particularly highlight the work of local healthcare managers, and their increasing attention to a set of key metrics about how CVD risk is being addressed.

Finally, in Chapter 9, I summarise the findings of this study, using the IE theoretical idea of ‘accountability circuits’. I circle back to illustrate how the GBD discourse (outlined in Chapter 2) organises frontline prevention practices; the accountability practices shown in Chapter 8 are directly articulated to epidemiological knowledge of GBD. I reflect more broadly on the findings of this study, considering the often detrimental impact of preventive practices, shaped by GBD discourse, on the ability of HCPs to engage in ‘meaningful conversations’ with patients about their health — to provide ongoing and adaptive preventive ‘care’. I discuss the value of the IE approach and this study’s contribution to knowledge about CVD prevention.

Chapter 2 Burden of Disease discourse and policymaking for CVD prevention

In Chapter 1, I presented Dan's story — a brief account of his preventive care. I drew attention to the 'fitting work' in which Dan got involved in order to fit institutional forms of CVD prevention into his everyday life. This included, for instance, doing his own research and assessing the benefits and potential problems with taking medications. When he looked for personalised support with this work from his GP, he received (what he felt to be) highly standardised advice. Perhaps more importantly however, the advice was "vociferous" (see Chapter 1), leading to a 'stand-off' between him and the GP, and fractured relationships within the health centre more generally. Dan's story provides an initial starting point for enquiry, and orientates the analysis presented (see Chapter 3). From here, I follow a trail into the mountain range (see 1.3). As I show through this analysis, the trail led me to discover how institutional knowledge about the 'burden of CVD' and its risk factors shapes local CVD prevention practices.

In this chapter, I helicopter straight to the complex of institutional arrangements within which CVD prevention practices operate, focusing particularly on 'global health' concerns about the 'burden of disease, and providing a view into the array of institutional practices that, I argue, coordinated aspects of Dan's experiences. First however, I ask the simple question, 'What is CVD?' I introduce CVD and its risk factors as diagnostic categories which, along with understandings of their prevention, are socially constructed within epidemiological 'forms of knowledge'. I then highlight 'global health' (and more specifically, 'global burden of disease' (GBD)) as institutional "spheres of activity" (Smith, 2014, p.225) which draw on vast epidemiological datasets with the aim of making population health visible internationally, and identifying opportunities to intervene. I situate this study as aligned with the concerns of critical global health researchers.⁸

⁸ However, this study only touches on the complex of social relations involved in the organisation of global and national population health improvement work. It is instead focused on showing how global health concerns enter into local, *frontline* prevention practices.

Utilising IE's concept of 'discourse', I examine how knowledge about the 'burden of disease' ('GBD discourse') enters into national policymaking about CVD prevention (and, through local tiers of management/policymaking, eventually into frontline clinical practices — as I will show in subsequent chapters). I draw on ethnographic analysis of policy and policymaking to show how national policymakers are increasingly drawing on GBD knowledge of populations. I highlight how a narrative is developed within the discursive practices of policymaking — of CVD as 'avoidable', and necessitating that frontline healthcare professionals and patients 'get serious' about prevention. Policymakers activate knowledge of global 'burden of disease' (GBD) metrics as part of this narrative, and as a resource to spur local policymakers/managers to prioritise particular forms of intervention — interventions which promise to both save patients' lives and healthcare costs.

As I proceed, I briefly introduce other important aspects of the social organisation of CVD prevention, selected for their relevance to the ensuing explication in the chapters which follow. This includes information about how English healthcare delivery is structured, and the types of interventions which have been put in place to prevent CVD. This background may be particularly useful to readers who are unfamiliar with English healthcare. In-keeping with the IE approach, I position the 'background' information provided in this chapter as 'data' (Rankin, 2017a), recognising that no knowledge stands as uncontentious or 'neutral' but is itself part of the social organisation of CVD prevention. As I build the arc of the argument presented in this thesis, I foreground GBD discourse because it became the focus of my inquiry as I started to uncover how experiences like Dan's are put together.

2.1 What is CVD?

I begin with some basics in relation to CVD and its risk factors — which as I will show are more complex than might be at first imagined. Medical understandings of CVD are based on epidemiological knowledge⁹. As Shim (2014) describes,

⁹ Epidemiology comes in various 'forms' — I use the term very broadly here.

“epidemiology is widely considered to be an authoritative mode of knowledge production on health risks and disease as well as a tool for policymaking”. It is therefore from an epidemiological standpoint that diseases (and the causes of these diseases) are defined, named, categorised and understood (Aronowitz, 2008). Within the epidemiological frame of knowledge, CVD is understood as a disease (or group of diseases) including: coronary heart disease; cerebrovascular disease; peripheral arterial disease; rheumatic heart disease; congenital heart disease; and deep vein thrombosis / pulmonary embolism (World Health Organisation, 2017b); all are diseases of the heart and blood vessels (NHS Choices, 2014). However, definitions vary and the definition of CVD may also include ‘risk factors’ such as: atrial fibrillation; Type 2 Diabetes Mellitus (T2DM); hypercholesterolemia; and hypertension (Public Health England, 2017b). These shifting definitions illustrate both CVD’s social construction as a set of individual diagnoses, and the evolving knowledge of each constituent diagnosis. Studies from the emerging ‘sociology of diagnosis’ (and others which apply a social constructionist ontology) have illuminated CVD’s social construction, and particularly highlighted the increasing representation of biomedical ‘risk factors’ (e.g. hypertension, hypercholesterolaemia, T2DM) as ‘diseases’ (Rosenberg, 2002; Aronowitz, 2009; Jovanovic, 2014).¹⁰ Epidemiological knowledge builds on these shifting diagnostic understandings, which are incorporated into international disease classifications (Goodyear and Malhotra, 2010).

The field of epidemiology known as ‘risk factor epidemiology’ (Greenland et al., 2004), which emphasises the role of variables associated with an increased risk of disease, is particularly important in authoritative understandings of CVD. Figure 1 provides an example of how CVD is represented by Public Health England, the ‘arm’s-length’ government body responsible for development and implementation of English public health policy. Here CVD is characterised as a

¹⁰ The increasing categorisation and management of T2DM separately to CVD may explain why it is not included as a ‘behavioural risk’ in Figure 1.

consequence of multiple 'risk factors' which are divided into 'behavioural' or 'social/environmental'.

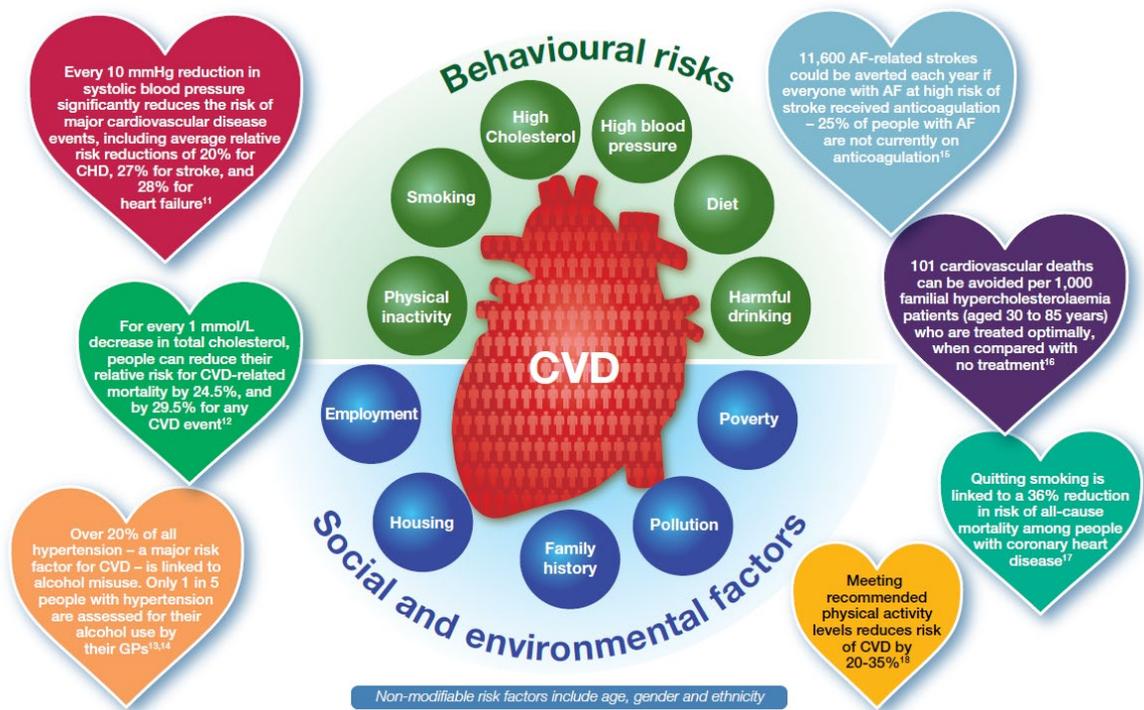


Figure 1: Key risk factors for CVD (Public Health England, 2016a)

Risk factor epidemiology emerged from studies such as the highly influential 'Framingham study'¹¹, a prospective cohort study examining the influence of "bodily traits" and "lifestyle habits" on the incidence of CVD (Shim, 2014, p.53). Developed from these origins, the official conceptualisation in Figure 1 divides population risk factors for CVD into those which are considered to relate directly to the characteristics of individuals, and those which relate to 'social and environmental' risks. Factors characterised as individual 'behaviour' (as opposed to factors such as age, or genetics) are particularly emphasised as causing 'cardiovascular events', most notably heart attack or stroke — the major causes of premature disability or death associated with CVD (British Heart Foundation

¹¹ This was a longitudinal study, operational for six decades from 1940s, and based on the population of the US city of Framingham. It included a total cohort of 5209 participants (Framingham Heart Study 2017).

and Nuffield Department of Population Health, 2015).¹² Although recent epidemiological studies (e.g. the Global Burden of Disease study — see below) have increasingly highlighted risk factors associated with the ‘social determinants of health’¹³ (Marmot and Wilkinson, 2005), the concept of risk factors has in general been “brought within a theory of health promotion directed to individual lifestyles” (Davis and Gonzalez, 2016, p.10). Citing Aronowitz (1998), Davis and Gonzalez argue that risk factors, although “derived from epidemiological observations, ‘are understood, and legitimised, only as they contribute to the specific, localised pathogenic processes that cause disease’” (ibid.). Epidemiology has in this way been *coupled* with biomedicine rather than explicitly *challenging* it or significantly modifying the practices associated with it.

However, whilst behavioural risk factors are understood within epidemiological approaches as being somehow ‘causational’ (paradoxically through epidemiological studies showing ‘association’), the underlying mechanisms of CVD are still not well understood (Stampfer et al., 2004), and are indeed hotly debated within some sections of the scientific community (see Chapter 4). There is however considerable scientific consensus that associates CVD with the process of atherosclerosis (inflammation inside an artery that causes fatty deposits and the artery to ultimately harden and narrow). As the early stages of this process are asymptomatic (and blood vessels are hidden inside the patient’s body), atherosclerosis “develops over many years and is usually advanced by the time symptoms occur, generally in middle age” (World Health Organisation and UNAIDS, 2007). So-called ‘biomedical risk factors’ are widely understood to accelerate pathogenesis, and so their identification in an individual is thought to indicate that atherosclerosis is “smouldering” within their body (Falk, 2006) — i.e. the process of atherosclerosis is taking place even though it cannot itself be easily seen using current technologies in use. Potential new risk factors, to be included within authoritative policy explanations of CVD, continue to emerge (Nieto, 1999). There are many critiques of individualistic ‘risk factor epidemiology’ which centre

¹² Sometimes (confusingly) these events are presented as CVD itself.

¹³ The evolving ‘subdiscipline’ sometimes known as ‘social epidemiology’ (Wemrell et al., 2016).

on issues of causal inference, validity, and individualisation (Rothstein, 2003). While compelling, these discussions are largely beyond the scope of this thesis. However, they underlie the evidence, and the debates, reviewed in Chapter 4.

2.2 'Global health' and the Global Burden of Disease project

'Global health' has been defined as "collaborative transnational research and action for promoting health for all" (Beaglehole and Bonita, 2010). At its historical "core" is improving the health of people in economically less developed countries (Packard, 2016, p.7). However, "the concept of global health has moved on from focusing on the problems of low and middle income countries (LMICs) to encompass health problems with global impact" (Nicholson et al., 2015, p.xix) — notably non-communicable diseases. Addressing the problem of chronic (or 'non-communicable') diseases through preventive action has become a priority within international, 'global' efforts, as chronic diseases have come to be understood as accounting for an increasing proportion of 'burden of disease' worldwide (Lopez et al., 2006). The term 'burden of disease' refers to epidemiological knowledge about the patterning of disease across populations, which has increasingly been foundational to population health management (Mykhalovskiy, 2001). Knowledge of the burden of disease has been made possible by digital technologies which have the capacity to store, process, and sort large quantities of data — data from vast epidemiological studies, from routine surveillance (e.g. national and international mortality databases), and from pioneering research studies (e.g. the Framingham study).

Of particular importance in the global health endeavour is the Global Burden of Disease (GBD) epidemiological study (Lopez et al., 2006), which has been described as the "world's largest publishing collaboration in science" (Global Burden of Disease study 20th Anniversary, 2017), involving over 2,300 researchers from more than 130 countries to collect and analyse data (Institute for Health Metrics and Evaluation, 2018a). Launched by the World Bank and the World Health Organisation in 1991 (Murray and Lopez, 2013; World Health Organisation, 2017a), it is now hosted by the Institute for Health Metrics and Evaluation in Washington, DC. GBD (the main product of the study) is the principal standardised "framework for integrating, validating, analysing and

disseminating the fragmentary, and at times contradictory, information that is available on a population's health" (Lopez et al., 2006, p.1). The GBD project quantifies the health effects of diseases and injuries for different regions of the world by collecting, validating, analysing, and publishing data to facilitate comparisons between populations for the purpose of health decision-making and planning (World Health Organisation, 2017a). It released its first global health data two decades ago (see Global Burden of Disease study 20th Anniversary, 2017) and periodically publishes complete new datasets and annual updates. The project aims to drive improvements in health across the world, by using "sophisticated analytical tools to generate comparable estimates for everything killing us or making us sick" (Global Burden of Disease study 20th Anniversary, 2017). Its scale and influence is indicated by the number of research articles it has generated — more than 16,000 peer-reviewed publications, cited more than 700,000 times at the time of its 20th anniversary (Institute for Health Metrics and Evaluation, 2018b).

The GBD project collates data from nation states on mortality, morbidity, and (more recently) on 79 'risk factors', which include a wide range of 'environmental' and 'behavioural' (including 'metabolic') factors which have been attributed to a range of diseases (Institute for Health Metrics and Evaluation, 2018b).¹⁴ Each nation state participating in GBD uses GBD methodology to produce the required national datasets, consolidating data from a variety of agencies (Public Health England, 2015b). Standardising and interpretative technologies are then applied to these data as part of the GBD international collaboration. When these data have been standardised, they are published in the form of key metrics, which enable and encourage comparisons of different nations and regions. The objective is to highlight health needs and spur governments and donors into action.

¹⁴ Some of these 79 risk factors correspond to the CVD risk factors shown in Figure 1. E.g. 'Metabolic' risk factors include: high fasting plasma glucose; high total cholesterol; high systolic blood pressure; and high body-mass index (Institute for Health Metrics and Evaluation, 2018b).

Chapter 2 The global burden of cardiovascular disease

GBD metrics enable international organisations such as the WHO and national policymakers to assert, for instance, that “CVDs are the number 1 cause of death globally: more people die annually from CVDs than from any other cause” (World Health Organisation, 2017b) — see Chapter 1. The GBD project, however, goes further than just counting the causes of death. Adams (2016, p.27) describes the Global Burden of Disease index (abbreviated to GBD) as “the most important metric [or set of metrics] of them all”. This is because, to use a senior proponent’s definition, GBD is “a **systematic scientific** effort to quantify the **comparative** magnitude of **health loss** due to diseases, injuries and risk factors by age, sex, geographies for specific points in time” (Speyer, 2013) (emphasis in original). This is achieved through calculation of a statistical product, Disability Adjusted Life Years (DALYs), itself calculated from measures of ‘premature mortality’ (Years of Life Lost) and ‘disability’ (Years Lived with Disability) (Lopez et al., 2006) — see Figure 2.

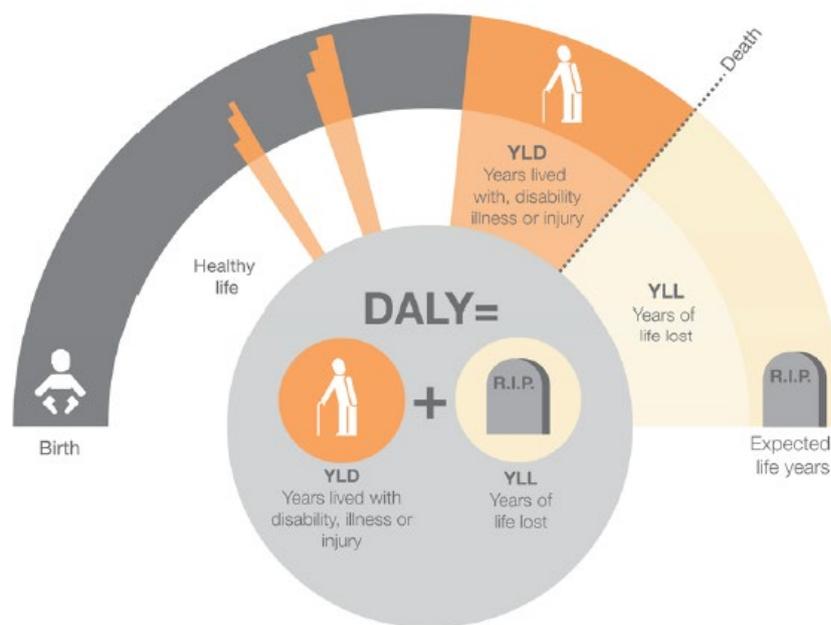


Figure 2: Measuring 'burden of disease' (Newton, 2015)

The GBD index (made publicly available online at GBD Compare (Institute for Health Metrics and Evaluation, 2017)) enables analyses and visualisations of the burden of disease in a population attributed to particular risk factors — as shown,

Chapter 2 The global burden of cardiovascular disease

for instance, in Figure 3. An alternative visualisation in Figure 4 shows how GBD data can be cut differently to show the impact of particular individual risk factors.

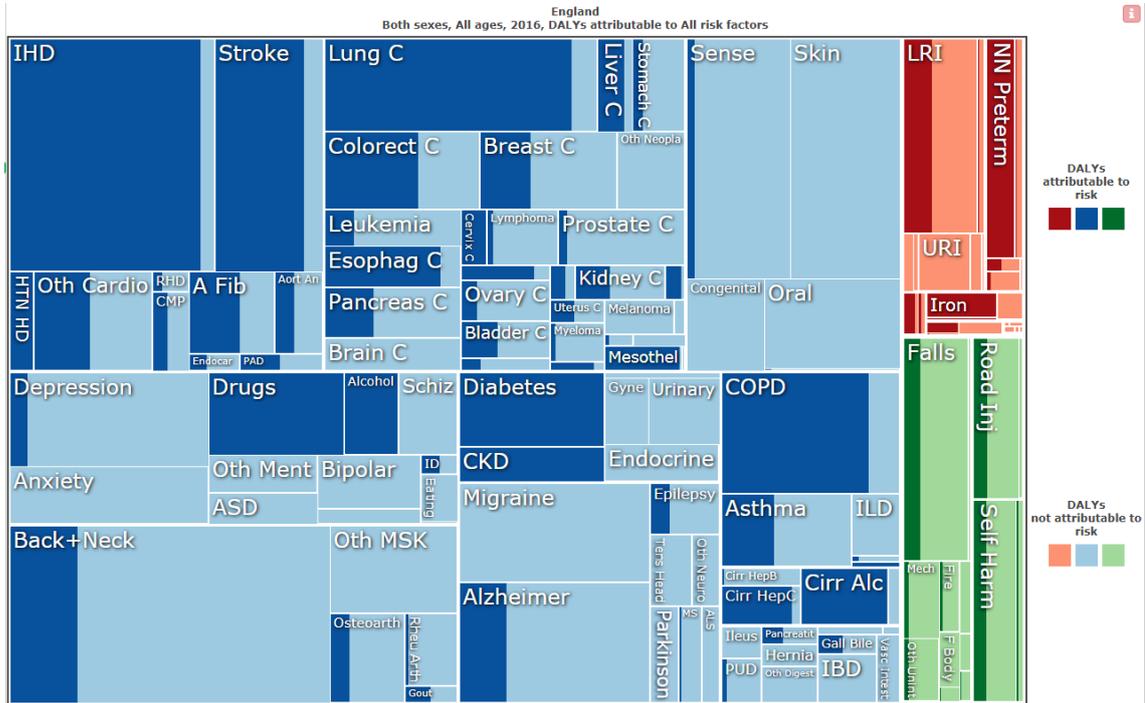


Figure 3: Treemap showing the 'burden of disease' (in DALYs) attributable to all risk factors (dark shades represent DALYs "directly attributable to risk") (from Institute for Health Metrics and Evaluation, 2017) (2013 data for England)

Chapter 2 The global burden of cardiovascular disease

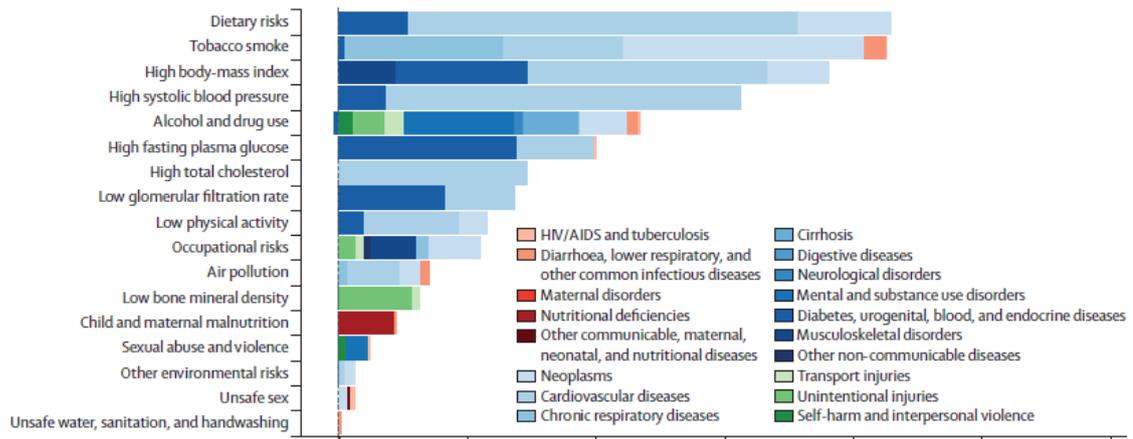


Figure 4: Burden of disease (in DALYs) attributed to 'level 2'¹⁵ risk factors based on GBD data (from Newton et al., 2015) (2013 data for England)

Knowledge of GBD is particularly useful to policymakers/managers interested in preventing chronic diseases, as these are understood to be costly to treat due to the often-prolonged period of disability and the associated costs of treatment — primarily acute (hospital-based) interventions (Bhatnagar et al., 2015; Newton, 2015). Public Health England, for instance, promotes its work with headline statements such as “CVD accounts for more than 15% of total DALYs in England, the second largest disease burden in the country” (Public Health England, 2016a).

Although the ‘burden of disease’ is technically the product of an equation, believed to provide a sophisticated resource for healthcare planning and intervention (see Figure 2), the concept ‘burden of disease’ (sometimes translated as ‘burden of illness’) is frequently applied more loosely, being used for instance to refer to contributory mortality or disability statistics, or to the costs associated with the use of healthcare services. For instance, it is more simple mortality data which provides the statistic that CVD is “the number 1 cause of death globally” (World Health Organisation, 2017b), and it is a combination of mortality data, indicators of ‘disability’ (e.g. hospital episodes), and financial costs

¹⁵ ‘Level 2’ refers to a calculative hierarchy of 3 levels of risk factors, most of which are in level 2 (Institute for Health Metrics and Evaluation, 2013). This is not important to the analysis here but is included for accuracy.

which feed into British Heart Foundation ‘headline statistics’ (2015). In Figure 5, burden is converted to a cost of £6.8 billion per year.

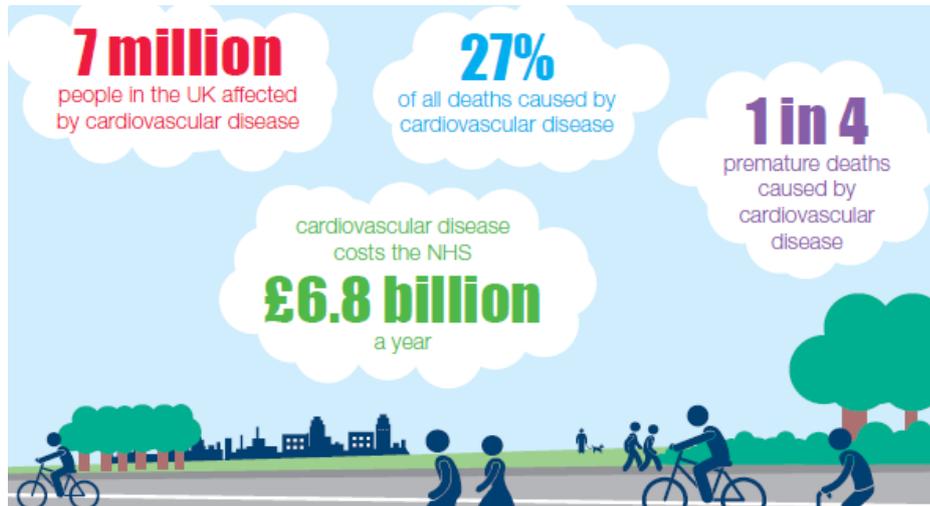


Figure 5: The problem of CVD (Public Health England, 2016a)

Global health has been described as “not yet a discipline but rather a collection of problems” (Farmer et al., 2013), but critical global health researchers such as Weir and Mykhalovskiy (2010, p.169) have documented the “depth of the change” which the “international public health reasoning and practice” of global health work has brought about. They highlight how population health management has shifted away from the sovereign control of nation states, to a new bio-political governance operating “beyond the sovereign” (ibid., p.20). Similarly, Packard (2016, p.6) notes that global health is “a multibillion-dollar enterprise [...] funded by large multinational organisations such as the World Bank, UNICEF, the World Health Organisation” and also supported by many public/private partnerships and private philanthropies such as the Bill & Melinda Gates Foundation. Through its use of seemingly ‘objective’ standardised metrics, projects like the GBD study, although a political accomplishment, have claimed political neutrality (Adams, 2016, p.9). However, as those working within the GBD study recognise (but others outside may not), both collecting and standardising data are fraught processes full of gaps, interpretations, and estimations (Speyer, 2013). In addition to the difficulty of getting “good numbers to fill the [equations] variables in the first place”, Adams describes the “arithmetic gymnastics” required to link people’s experienced health with economic models using these equations (e.g.

the necessity of assigning values to life with different conditions) (Adams, 2016, p.28).

In 2.4 below, I discuss in more detail how English policymakers and other interested parties utilise the ‘facts’ of GBD. First however, I introduce the theoretical approach that I use to examine the influence and reach of GBD knowledge.

2.3 Burden-of-disease discourse as a technology of management

This study is situated within a corpus of IE work documenting the operation of managerial practices in healthcare — that IE scholars have framed as a form of ‘New Public Management’ (NPM)¹⁶. This IE scholarship has shown “how new managerial practices are imposed and operate in public sector services in which the major work focus for realising objectives is done at the front line” (Griffith and Smith, 2014b, p.7). Griffith and Smith argue that frontline work in organisations delivering services to people has become increasingly dominated by management technologies; complex ‘social relations’ developed remotely from the frontline that are inserted into frontline work in order to make services more efficient. This thesis explicates the social organisation of frontline experiences such as those of patients like Dan (see Chapter 1). Utilising IE’s ontology, I highlight the role of what I call ‘GBD discourse’ (see below) as a ***technology of management*** and central to this social organisation. I show how knowledge of GBD is ‘taken up’, and sometimes reformulated, by national policymakers and local managers in order to produce localised “knowledge for taking action” (Rankin and Campbell, 2006, p.7).

2.3.1 ‘Discourse’ in IE

It is helpful here to divert briefly and consider how the concept of ‘**DISCOURSE**’ is used within IE, prior to returning to GBD discourse more specifically. Smith

¹⁶ Griffith and Smith draw on various writers in their use of the term ‘NPM’. In line with their application, I understand NPM as “a loose term”, whose “usefulness lies in its convenience as a shorthand name for the set of broadly similar administrative doctrines which dominated the bureaucratic reform agenda in many of the OECD group of countries from the late 1970s” (Hood, 1991).

(2014) draws on Mikhail Bakhtin's notions of 'dialogics' and 'speech genres' in her explanation of "discourse as social relations":

"Discourse [...] is recognised as relations coordinated by texts, a secondary speech genre in Bakhtin's terms, but discourse is also itself a sphere of activity, of the doings of actual people who are actively engaged in utterances, their own and others'." (Smith, 2014, p.227).

Smith's approach recognises that speech in various forms is fundamental to the organisation of 'the social' and it therefore has a very particular application in line with IE's ontology. In IE, 'discourse' is not a synonym for 'language' or 'speech', but these concepts are integral to it. Smith's conception of discourse includes both simple forms of speech ('utterances' which are written, spoken, or thought "in and of direct encounters between people" (Smith, 2014, p.227)), and also language which is resident in texts (a 'secondary speech genre'). Following Bakhtin, she understands **language as "coordinating consciousness"** (Smith, 2005b, p.77) — the consciousness of individuals involved in 'work' (using IE's "generous concept" — see 1.2). Indeed, she argues that "the distinctive forms of coordination that constitute institutions are in language" (ibid., p.94).

Using Smith's approach, the term 'discourse' is particularly relevant when utterances or texts can be seen to have become standardised "from many sources and over time" (Smith 2014, p.231). However, as Smith contends in the extract above, discourse is not only "relations coordinated by texts", but also a **"sphere of activity"** — being *active* as people (e.g. research participants, researchers, academics, and so on) think, write, listen, and read. Smith's approach to language challenges lexical models which are, she says, "grounded in an experience of language as meaningful independently of its local practice among people". Instead, she argues that language (or discourse) "coordinates consciousness in ongoing courses of action" (Smith, 2014, p.225). Although it may be useful to identify a particular 'discourse' in an IE analysis, its fluidity should always be recognised — it is never 'a thing' which stands alone or is transmitted 'clean' from one local site to another, but is "essentially social" (2014, p.229) — always in dialogue with contemporary heteroglossia, with a "world full of other voices" (Smith, 2014, p.231). This notion of language and meaning (taken

from Bakhtin and others) as ‘dialogic’ or ‘double-sided’ (taken up and then transformed as words are transferred from one mouth/setting to another) is particularly important in this study — connections between frontline practice and ‘extra-local’ relations are frequently seen in discourse. (I discuss the related notion of ‘ideological discourse’ in 3.2).

Discourse then is a central feature of ruling practice in contemporary society and is also central to IE enquiry (DeVault and McCoy 2006). Its “peculiarity”, Smith claims, “is the standardisation of ways of producing utterances from many sources and over time that can claim membership in it” (2014, p.231). The IE approach to analysing, and using the term, ‘discourse’ is therefore different to various, often “loose”, contemporary approaches (Bacchi, 2005; see also Galasiński, 2014). In the section which follows, I provide a brief introduction to GBD as ‘discourse’, drawing on Mykhalovskiy’s (2001) IE-informed analysis of Health Services Research (HSR).¹⁷

2.3.2 GBD as ‘active discourse’

To this point, I have focused on GBD as a textual form of knowledge known as ‘metrics’ (Adams, 2016), and provided a brief introduction to the production of these metrics. Here I argue that GBD metrics do not stand alone but are important constituents of a bigger ‘GBD discourse’, consisting not only of texts, but of talk and (crucially) people’s *activities*. Similarly to Adams’ (2016) and others’ critical global health analyses of how metrics are appropriated for particular ends, Mykhalovskiy (2001), drawing on Smith’s understanding of discourse, describes how Health Services Research (HSR) presents “forms of intelligibility” which “render health care amenable to certain forms of managerial practice”. Understanding HSR as “applied and multidisciplinary” and as employing “the conceptual and methodological resources of epidemiology, biostatistics, economics, and other disciplines to create knowledge about the delivery of healthcare services”, Mykhalovskiy notes that HSR relies on “various calculative

¹⁷ I discuss two distinct ‘spheres of activity’ (relations coordinated through language and texts) in this study: I call them ‘GBD discourse’ and a related ‘risk management discourse’ (Chapter 4) for ease of presentation.

practices, forms of numerical representation and narrative commentary” to shape healthcare practices as “a patterned universe of increases, decreases, and dispersions” (ibid.). HSR data, according to Mykhalovskiy, is activated as ‘discourse’ — characterised by its standardised forms of language and knowledge — as people participate in it. It becomes a powerful coordinator of people’s activities.

Within this understanding of discourse, I understand GBD metrics as “textual products” (Smith, 2014, p.234) of GBD discourse — itself a variant of Mykhalovskiy’s ‘HSR discourse’. Metrics have been defined in a non-specialist sense as “[standards] for measuring or evaluating something, especially [using] figures or statistics” (Dictionary.com, 2018). An alternative conceptualisation, suggested by Adams (2016) in relation to their role in managing population health (see below), is that they are “technologies of counting” which “are imagined to offer uniform and standardised conversations about how best to intervene, how best to conceptualise health and disease, how best to both count and be accountable, and how best to pay for it all” (Adams, 2016, p.6). Adams and Biehl (2016) note that they therefore enable “geographically distant places [to be] sutured together by the larger structures of science, finance, and policy that claim the mantle of global health”. Adams’ anthropological analyses recognise that metrics transform and simplify the so-called ‘big data’ (Groves et al., 2013) from population surveillance — they are *selectively* “lumped together” (Adams, 2016, p.6) for management purposes.

Adams’ (2016) collection of ethnographic studies demonstrates that GBD metrics add a highly visible, and simplified overlay to the ‘patterned universe’ of HSR — by elevating particular indicators of performance, which seem to represent neutral accounts of the ‘real world’ but which are laced with all kinds of politics and managerial imperatives relating to ‘efficiency’ and cost savings. These are the indicators against which politicians and healthcare managers in different locations may be held accountable. I use the term ‘GBD metrics’ here to highlight both GBD statistics (measured in DALYs), and also their constituent metrics such as mortality, disability, or population measures of ‘prevalence’ (see Figure 2 / section 2.4 below). Other “more complex modes of numerical figuring” (Adams,

2016, p.11), such as risk algorithms, QALYs, and the like are also embedded as part of this statistical complex, providing knowledge of how policymakers should intervene. I highlight the significance of these additional metrics, as the basis for a suite of risk management interventions, in the analysis below.

GBD discourse then is an ‘**active discourse**’ (Mykhalovskiy, 2001) on which policymakers, managers and the like draw in order to choose and justify certain forms of action.¹⁸ As Mykhalovskiy puts it, “the accounts of healthcare practices [HSR] produces are not made for philosophical or theoretical reflection, but for the pragmatic work of 'improving' health care” (ibid.). Mykhalovskiy’s critique of HSR is relevant here as he shows that many actors (policymakers, researchers etc.) draw on HSR as a fixed and ubiquitous “conceptual resource” (i.e. as an objective frame of reference) which cannot readily be challenged. He argues that the discursive frame of HSR is so strong that even those offering *critiques* of HSR may only challenge what they consider to be biases in its *production*, rather than interrogating the validity of the *form of knowledge* contained by the discourse. Characteristically, he argues, researchers base their underlying knowledge of their field on the assumptions of the HSR discourse. Even in critical approaches (e.g. analysing the power of the ‘state’ or the medical profession), HSR “appears as significant [...] **only as a resource or tool in a contest for power**, which is the main object of analysis” (emphasis mine). The knowledge contained within the resource itself (HSR) is not the focus of these researchers’ analyses. Mykhalovskiy’s concern is echoed by Pigg (2013), who similarly argues that global health researchers (and even seemingly critical ethnographers) may “foreclose directions of inquiry that might emerge through ethnographic discovery by prematurely containing what should be investigated within the allowable terms and values of dominant global expertise and a concomitant set of already legible criticisms”.

Building on Smith’s insights, Mykhalovskiy (2001) proposes that instead of taking up HSR knowledge as a ‘conceptual resource’, it should be explored as a

¹⁸ Similarly GBD discourse can be conceived as a “sphere of activity” in which people participate (see 2.3.1).

“practical exercise of power” which “helps to order activity in health care through the questions it asks and the forms of visibility of health care it offers, all of which are a consequence of the particular configuration of calculative practices, narrative strategies and forms of expertise” (2001, p.153). The data and the analysis presented in the subsequent chapters show GBD discourse (a variant of ‘HSR discourse’) as a dominant organiser of frontline experiences. IE’s theoretical framework provides a way to identify how GBD knowledge is activated as practices across the different ‘locations’ in which people work to ‘prevent CVD’ — whether national/local policymakers, frontline HCPs, or patients. GBD discourse is much more integrated into people’s work than suggested by research analyses which point to a “masterplan of rule” (2001, p.152) or the “negation or the support of a given interest” (2001, p.158). Instead, understanding GBD as ‘active discourse’ opens it up as an institutional sphere of activity in which policymakers and others are actively engaged; it enables analysis of *how* policymakers take up this knowledge, and examination of *how* CVD prevention is organised by specific ideas and interests, and *with what consequences*.

2.4 Creating a GBD ‘story’ in English prevention policy

Over recent years, systematic efforts have been made to integrate GBD knowledge into English policymaking (Department of Health, 2013a). The work of English policymakers at a national level is orientated to international competition between countries which has been enabled, and promoted, by the production of standardised GBD metrics. In the policy paper ‘Living Well for Longer’ (Department of Health, 2013c), the then Secretary of State for Health (Jeremy Hunt) expresses “shock” that “too many people in this country are dying too young from diseases that are largely avoidable”, basing his comments on published GBD comparisons between countries (Murray et al., 2013). He continues, “I want us to be up there with the best in Europe when it comes to tackling the leading causes of early death”. This competitive language is picked up by CVD national leadership when they express their concern, for instance, that “the UK lagged behind many other western industrialised countries in reducing premature mortality rates” (Fenton, 2014).

English involvement in GBD is understood to be a mutually beneficial collaboration, as “international engagement is vital to ensure Public Health England remains a global leader, providing state-of-the-art public health services and advice within the UK and internationally” (Public Health England, 2014b); English researchers have actively collaborated in the project over recent years (Murray et al., 2013; Newton et al., 2015). Although many of the English organisations responsible for collecting and organising epidemiological data predate GBD, collaborative GBD work has led to new organisational structures and accountabilities (see below). Public Health England has increasingly invested in it, and contributed to influential publications comparing UK health trends with those in other countries (Murray et al., 2013). As Newton (a leading researcher of English burden of disease) extols, this data “has played a crucial role in influencing health policy, impacting research and educating us on where we need to focus our energy to make the biggest difference to the public’s health. It is a fantastic example of where research meets policy and how decision making can be impacted by evidence” (Newton, 2017).

Crucial to this work has been the establishment of a National Cardiovascular Intelligence Network (NCVIN) in 2013. As the Chief Knowledge Officer (Reducing Preventable Deaths) has explained (Ferguson, 2013), the more knowledge of populations and healthcare services is available, the greater the ability of policymakers to drive improvements:

*“English philosopher Sir Francis Bacon once said, ‘**knowledge is power**’. The more of it we have, the better informed and equipped we are to address any issues and drive improvements. And this too is true for health. Within Public Health England, much of this knowledge exists within our new and emerging health intelligence networks [...]”. (Emphasis mine)*

The stated aim of the NCVIN is to use GBD knowledge to “improve the quality of care and outcomes of communities, patients and their families” (Public Health England, 2013a). According to Ferguson (2013), English health leaders are supporting this aim by operating “across organisations bringing together various holders of information, national charities, NHS partners, researchers and key users of health intelligence”, and also work with other organisations “to help

strengthen knowledge translation locally using tools and resources with national expertise”. Linking different sources of GBD metrics into health governance is central to leaders’ work and is claimed to enhance the NCVIN’s ability “to use authoritative data as a powerful information source for healthcare professionals and policy makers, as well to improve public health outcomes surrounding these conditions” (Public Health England, 2013a).

The ‘intelligence’ from GBD metrics however (as highlighted above) consists of huge datasets which can appear as “dry data” (see 2.5 below). In order to drive health improvements in practice, national leaders therefore supplement knowledge through GBD metrics into a “**story**” (Kearney, 2016b) designed to guide local policymakers and “[have] meaning” for frontline HCPs. In particular, the idea of ‘**avoidable disease**’ permeates both international and English CVD prevention policy, as demonstrated in the Secretary of State for Health’s comments above (see also World Health Organisation, 2007; World Heart Federation, 2015; Department of Health, 2013a, 2013c; Public Health England, 2016a). The idea of ‘avoidable disease’ has been built on the statistical construct of ‘avoidable mortality’¹⁹, and broadly indicates the burden of disease which may be influenced through Public Health or medical intervention on CVD risk factors (Eurostat Statistics Explained, 2017). In this *general use*, terms such as ‘avoidable’, ‘preventable’ and ‘modifiable’ are used flexibly to tell a story about particular risks which are contributing to the nation’s burden of disease — a story

¹⁹ ‘**Avoidable mortality**’ is a statistical category based on GBD mortality data, and is one of the most obvious ways in which GBD metrics enter into policy. It is a technical construct comprising ‘**preventable mortality**’ (addressed through “public health interventions encouraging people to take more exercise or stop smoking, or in tackling the wider social determinants of health” (Department of Health, 2013c)) and ‘**amenable mortality**’ (addressed more specifically through “health care interventions such as early diagnosis of diseases or conditions and through effective treatment” (ibid.)). Simply put, addressing preventable mortality (or more broadly ‘disease’ or ‘illness’) corresponds with what is sometimes described as ‘primary prevention’ (“designed to reduce the instances of an illness in a population and to reduce their duration” (Public Health England, 2016a)), and addressing amenable mortality corresponds to ‘secondary prevention’ (“aimed at detecting and treating pre-symptomatic disease” (ibid.)). (Definitions of primary, secondary, and tertiary prevention are various in policy, and I mention them only briefly here as the terms appear in other parts of this thesis.) In theory, these early forms of prevention in the population should reduce the need for subsequent ‘tertiary prevention’ (“activities aimed at reducing the incidence or recurrences of chronic incapacity among those with symptomatic cardiovascular disease” (ibid.)).

which built on the quantified metrics of GBD and the form of knowledge within the GBD discourse.

Although the statistical concept of ‘avoidable disease’ is concerned with governments’ responsibilities to provide public health and medical services (Eurostat Statistics Explained, 2017), English policymakers have increasingly also focused their attention on the responsibility of individual patients and frontline HCPs to do more to address the problem. The influential Wanless Reports to the UK government (2002; 2004) called for a “**fully engaged scenario**” in which the public had a high level of engagement in their own care, and demanded high quality, efficient health services to support this. Drawing on these reports, the authors of the ‘Five Year Forward View’ (NHS England, 2014a) subsequently contended that “the future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health”. They rebuked ‘the country’ for not contributing to Wanless’ ‘fully engaged scenario’ and not taking prevention “seriously”, arguing that, due to the inaction of individuals (“who are ultimately responsible for their own and their children’s health” (Wanless, 2004)), as well as the inaction of the healthcare community (of commissioners and providers), there was a “sharply rising burden of avoidable illness” and the NHS was “on the hook” financially (NHS England, 2014a). Policymakers have consistently reiterated this message that individuals and HCPs need to “get serious about prevention” (Fenton, 2015; Public Health England, 2016a; NHS Health Check, 2016a), locating the primary problem as a lack of commitment to healthy living and (supporting) changed lifestyle behaviours. Ultimately, frontline HCPs and patients are positioned within these policy narratives as responsible for addressing the financial predicament of the NHS (see 2.6).

The GBD story, which started with ‘avoidable disease’, has been developed by policymakers as a tale of various actors (local policymakers, HCPS and patients) who are not ‘**taking prevention seriously**’. It is a story with a moral narrative which has become the basis for new initiatives such as ‘All Our Health’ (Bennett, 2016). Still in its infancy during this study, the All Our Health framework has been designed to support HCPs to address *avoidable illness* through, in part,

increasing ‘wellbeing’ and ‘resilience’ in their patients — *individual qualities* which policy presents as being particularly lacking in deprived communities (see, for example, South, 2015). Through harnessing GBD with the responsabilising narratives of ‘avoidable disease’ and the need to ‘get serious’ about prevention, policymakers particularly highlight the problem of poor ‘lifestyles’ (see Hansen and Easthope, 2007) — and perhaps also extend the reach of healthcare services to attend to the moral character of individuals.

The NCVIN’s work has been particularly directed at making GBD metrics *visible* in order to facilitate comparisons between English regions and promote competition. In 2015, Public Health England promoted the new ‘GBD Compare England’ tool, which enables national and local policymakers in England to “rank the burden of disease for 306 conditions from 1990-2013 by region and deprivation, along with the relative impact of 79 different risk factors” (Public Health England, 2015a). Data can be manipulated, segmented, and presented in multiple graphic formats to suit their particular needs. They are designed to promote competition between similar local commissioning organisations around their success or otherwise at reducing the burden of disease. This competition is enhanced by making the data rankings visible to the general public (see e.g. Public Health England (2017c, 2017d) and NHS RightCare (2016)).

By making metrics visible, and applying the language of ‘avoidable’ to them, policymakers spotlight this statistical knowledge of the *disability* and *cost* burdens of CVD and its risk conditions. GBD metrics are produced not only as ‘facts’ but also as demanding a *moral response* from everyone who could potentially be involved in CVD prevention activities (see, for example, World Health Organisation, 2010b). As Wendland (2016, p.78) observed when studying the workings of mortality metrics in Malawi, “the product of an equation may look like a number and work like a fact, but it is more like the moral of a story”. Or as Mykhalovskiy (2001) highlighted, numbers often do not work alone but are activated along with “narrative commentary”. Here, GBD, and allied global health metrics which stand like facts (see Figure 5), are accompanied by a narrative that CVD can and should be avoided and, as I will show below, other related narratives of how that should be achieved.

2.5 Communicating the GBD story to frontline HCPs

As introduced above, new English CVD policymaking structures have been created, whose purpose is to understand and address ‘avoidable disease’ utilising ‘health intelligence’ (GBD metrics) and also to engage local policymakers in this GBD activity. As part of the NCVIN’s work, a Primary Care CVD Leadership Forum was set up in 2015. This was led by Matt Kearney, National Clinical Director for Cardiovascular Disease Prevention, described as “a crucial GP voice at the centre of government plans to shift towards a more preventive health service” (Pulse Today, 2015b). According to Pulse Today, an online news service for GPs, the NCVIN’s primary focus has been to bring GBD knowledge to improve frontline practice, and therefore comprises approximately 30 so-called “jobbing GPs”²⁰ as well as nurses and pharmacists. The forum has been responsible for developing several tools and resources which allow local policymakers and managers to ‘know’ their populations and the effectiveness of local healthcare services. With the support of Public Health England, the NCVIN has for instance produced ‘intelligence packs’. One prominent member of the forum explains the importance of these packs:

“For each of the high risk conditions the packs use QOF²¹ and other data to show detection and management rates, comparing the CCG with demographically similar CCGs, and comparing neighbouring practices with each other. But the packs are not just about dry data. They are designed to tell a story that will have meaning for primary care clinicians – because it has been written by primary care clinicians.” (Kearney, 2016b)

As Kearney expresses it in the extract above, the work of national policymakers is to turn GBD metrics from “dry data” into a “story that will have meaning” — that local managers and HCPs can take up. In addition to the intelligence packs, a more complete range of electronic tools and resources, collated by Public Health

²⁰ Used within the profession to describe an ‘everyday GP’ (who works clinically rather than managerially (Primary Care Commissioning, 2013)).

²¹ QOF data relate to the management of chronic diseases and are collected from general practice electronic systems. These metrics are important in this study, and are introduced in 2.7.

England (2017b), are designed, like the intelligence packs, to “help doctors benchmark data, predict how outcomes will vary, and what questions GPs should be asking about local CVD services” (Pulse Today, 2015b). These have been produced in collaboration with NHS RightCare, which has turned its attention to prevention (Cripps, 2018). The NHS RightCare model is central to current CVD prevention policy and identifies three ‘phases’ to be conducted by local policymakers so that they can understand their populations and also promote and drive interventions locally which will deliver greatest value for money. These phases involve using national datasets to know **where to look** (e.g. through identifying the worst geographical localities using ‘variation modelling’), **what to change** (e.g. using datasets from healthcare providers), and **how to change** (e.g. through “business processes” to engage local clinical leaders) (Public Health England et al., 2014).

GBD metrics produced through the GBD project are positioned as particularly relevant for answering the question of ‘where to look’; as I have already shown, these form the basis of the intelligence collated by national policymakers. However, national policymakers also supplement the *internationally standardised* GBD metrics with those extracted more directly from English datasets — from which they have access to more granular data.²² (I include all these (variously obtained) metrics within my broad use of ‘GBD metrics’.) GBD metrics from English datasets develop the story of ‘avoidable disease’, localising the narrative about ‘what’ and ‘how to change’ which is taken up first by local policymakers, and then by HCPs. As I will show in Chapter 8, the concept of disease ‘prevalence’ or the ‘prevalence gap’²³ (conceptualised by Soljak and Flowers (2008)) is important in this story. This gap in particular provides estimates of undetected risk conditions / diseases in the population, and a rationale for action to improve detection and management of these conditions (Ghosh, 2016).

²² Some of these data sources (e.g. QOF datasets) also provide particular sets of specified data to the international GBD project.

²³ The prevalence gap is between ‘observed prevalence’ of particular risk conditions (the number of people these conditions as collected by healthcare services, primarily through the QOF payment system) and ‘estimated prevalence’ (modelled estimates of ‘true’ prevalence in the population e.g. those made by Public Health Observatories) (Walford, 2011).

Prevalence gaps for a selection of risk conditions frequently appear in national resources as “opportunities” for reducing the burden of disease (see NHS RightCare (2016) and *Figure 6* and *Figure 7* below). In Chapter 8, I show how such ‘opportunities’, presented as part of the GBD story, are textually communicated to (and heard by) frontline HCPs, through an analysis of the work of both HCPs and local policymakers.

2.6 A win-win strategy: saving lives and costs

Local policymakers’ knowledge of how to act to prevent CVD is closely tied to their epidemiological knowledge of the burden of disease and GBD metrics. Interventions which have been demonstrated (through research studies and economic analysis) to both benefit patients’ health, and do so at a reasonable cost, are known as ‘evidence based’ and are recommended in clinical guidelines. Authoritative understandings of such evidence based interventions are built, like ‘burden of disease’, on statistical calculations (see below). An overview of CVD prevention interventions, which policymakers understand will reduce the burden of disease, is shown in *Figure 6* and *Figure 7*; these are discussed in more detail in Chapter 4.

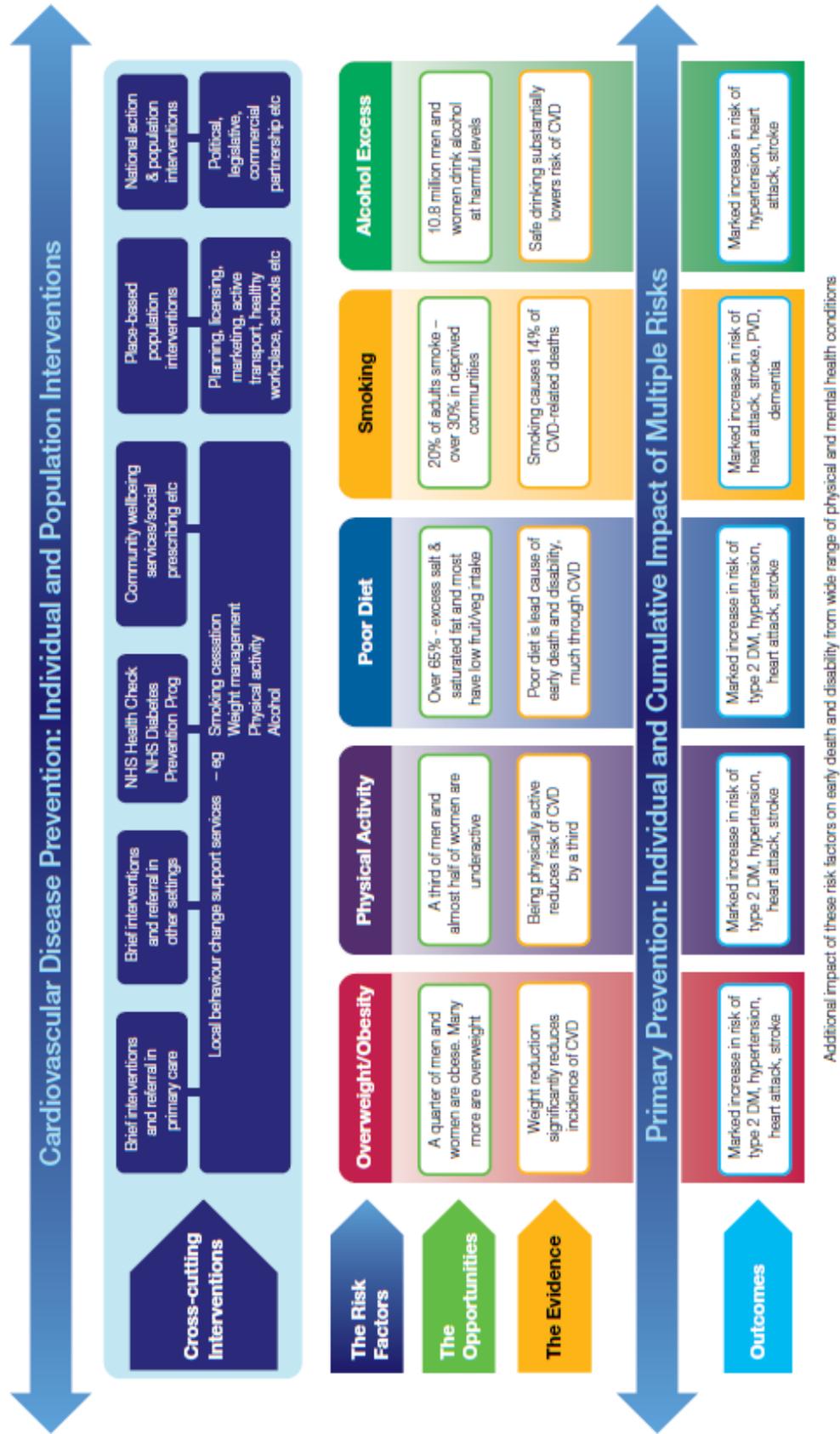


Figure 6: 'Primary prevention' (from Public Health England, 2016a)

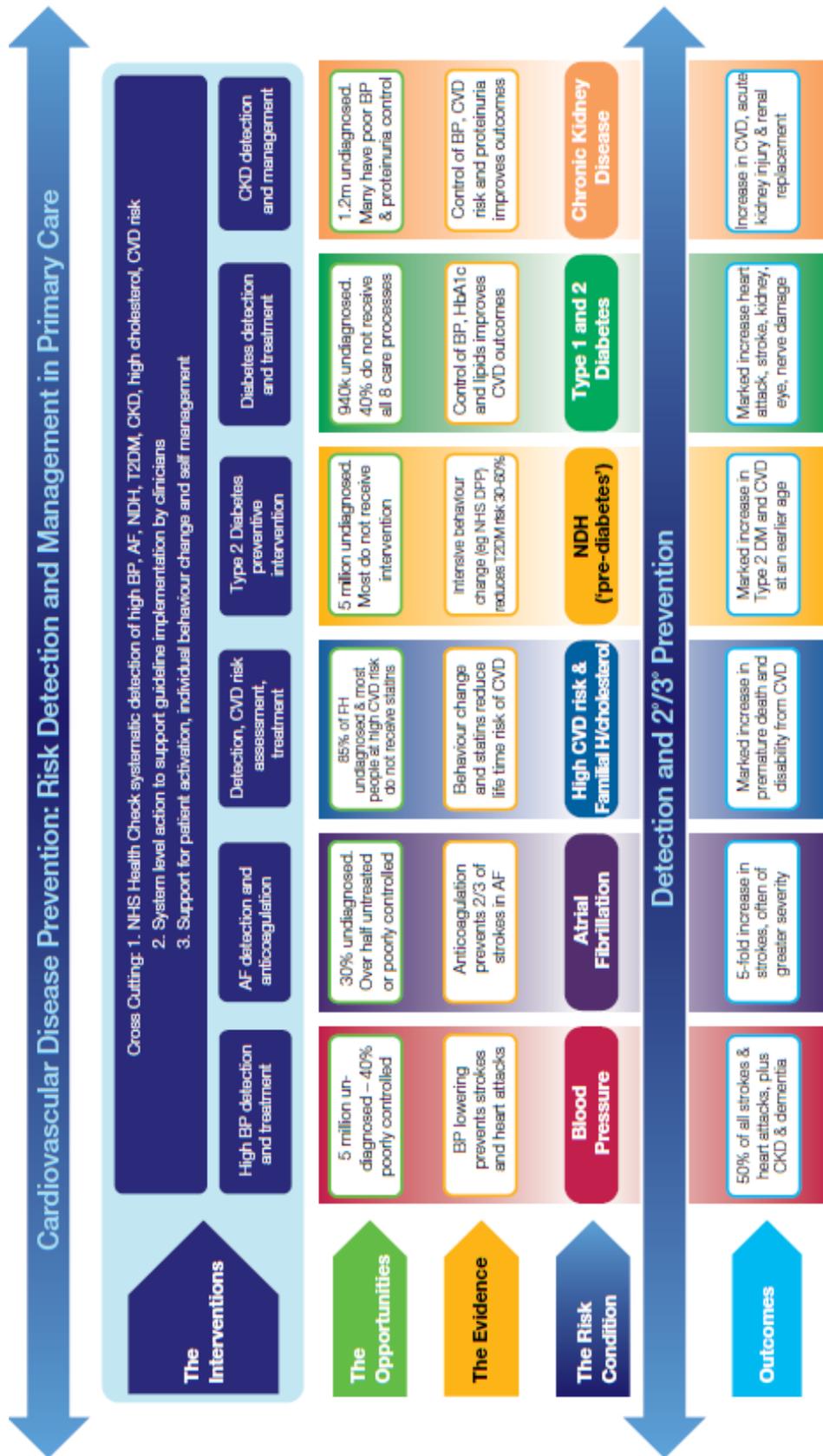


Figure 7 'Detection' and 'secondary'/tertiary prevention' (from Public Health England, 2016a)

The suite of interventions presented in these figures are understood to reduce the chances of developing CVD (or its ‘risk conditions’)²⁴. They are commonly divided into ‘lifestyle interventions’ and ‘medical interventions’ (see Chapter 4). Although many of the interventions shown are well-established as part of clinical care delivered in general practice, others extend beyond the opportunistic health promotion activities which have long been expected of HCPs (Stott and Davis, 1979; Boyce et al., 2010), and which are integrated into the GP contract (see NHS Employers et al., 2015). For example, the Health Check and lifestyle programmes in *Figure 6* and *Figure 7*, are supplementary to the core medical services contract with general practitioners (NHS Employers, 2016a), and are commissioned through a separate ‘public health’²⁵ funding stream, which is transferred direct to local authorities from a ring-fenced central government grant (Department of Health, 2016). (The structure of the NHS since commissioning reforms in 2013 is shown at *Figure 10*.) Local authorities must balance spending on the Health Check with other public health services such as health visitor services, sexual health services, and ‘lifestyle’ services. In common with most public services, the public health funding ‘pot’ distributed by local authorities has been cut in recent years; cuts amounted to £200 million for 2015/16 (Department of Health, 2016). Lifestyle programmes and the Health Check programme may be contracted to any qualified provider. However, the Health Check programme is often contracted to general practice providers — as is the case in the settings covered by this study. Delivering Health Checks provides modest, but significant, additional income to general practice (an average of approximately £25 per check²⁶). Throughout this analysis, I focus on the interventions which are delivered or coordinated through general practice. I particularly draw attention to the frontline delivery of the NHS Health Check — the primary intervention in English policy for ‘case-finding’ (identifying new cases of

²⁴ Although ‘risk conditions’ may also be classified as ‘risk factors’ or ‘diseases’, I use the term ‘risk condition’ when talking specifically of this subcategory of CVD risk factors which are understood to be abnormal, and often taken to indicate that a disease process has started.

²⁵ The term ‘public health’ is often used to describe the administrative form of ‘population health’ (The King’s Fund 2017).

²⁶ Figure based on the Health Check economic model (Department of Health, 2008a) and interview data. The cost per check has remained relatively static over the lifetime of the Health Check programme.

disease or risk which are authoritatively understood to require intervention and which will therefore address the ‘prevalence gap’).

As I have already noted, integral to the notion of evidence based interventions, is that they are not only ‘clinically effective’ but also ‘cost effective’. By demonstrating cost-effectiveness, and comparing one intervention with another, healthcare managers can pick the “best buys” — interventions which are “not only highly cost-effective but also cheap, feasible and culturally acceptable to implement” (World Health Organisation, 2010b). The underlying importance of cost-effectiveness threads through the key policy documents promoting CVD prevention. For instance, the Five Year Forward View (NHS England, 2014a), an important strategy document which sets out “a vision of a better NHS, the steps we should now take to get us there, and the actions we need from others”, postulates that central to “targeted prevention” are “proactive primary care” and “evidence based intervention strategies”. The authors argue that greater focus on early prevention through evidence-based interventions is a better “investment decision” than subsequent funding of treatment which could have been avoided. Cost effectiveness is particularly emphasised in CVD prevention policy and forms a fundamental part of all guideline recommendations (NICE, 2012a).

Economic modelling for the programme (Department of Health, 2008a) provides an illustration of how cost-effectiveness is calculated, based on multiple individual constituent calculations (see *Figure 8*).

$$\text{Cost effectiveness} = \frac{\text{Sum of } \left(\begin{array}{c} \text{Referrals} \\ (A) \end{array} \times \begin{array}{c} \text{Lifetime net} \\ \text{costs (A)} \end{array} \times \begin{array}{c} \text{Attribution} \\ (A) \end{array} \right) \text{ over all} \\ \text{interventions} + \begin{array}{c} \text{Cost of vascular} \\ \text{checks} \end{array}}{\text{Sum of } \left(\begin{array}{c} \text{Referrals} \\ (A) \end{array} \times \begin{array}{c} \text{Lifetime net} \\ \text{QALYs (A)} \end{array} \times \begin{array}{c} \text{Compliance} \\ (A) \end{array} \times \begin{array}{c} \text{Attribution} \\ (A) \end{array} \right) \text{ over all} \\ \text{interventions}}$$

Figure 8: Calculation of Overall Cost Effectiveness for the Health Check (Department of Health, 2008a)

Crucial to such calculations of cost-effectiveness is the statistical construct of Quality Adjusted Life Years (QALYs) which indicate ‘quality of life’ in relation to ‘full health’. ‘QALYs gained’, or ‘lifetime net QALYs’ (*Figure 8*), provide evidence of the benefit of the intervention in question, as calculated from the findings of research

studies, and (broadly speaking) are the inverse of DALYs (NCCID, 2015) (2.2).^{27,28} The logic of CVD prevention is not only that the incremental cost effectiveness ratio (ICER) (Bambha and Kim, 2004) is calculated to be good value for money, but also that, for some interventions, it demonstrates net savings (i.e. where cost savings outweigh intervention costs over a lifetime and are deemed to be a “return on investment” (Optimix Matrix, 2014; Public Health England, 2016c)). Where net savings can be established, the benefit of implementing the intervention is understood to be “unequivocal” (Optimix Matrix, 2014).²⁹

As a result of economic modelling of the Health Check, Public Health England (2016e) was able to claim that the check was “cost effective with potential savings to the NHS of around £57m per year after four years, rising to £176m per year after 15 years”. Crucially, this modelling contributed to the widely circulated headline statistics that the Health Check programme would “**prevent 1,600 heart attacks and strokes and save at least 650 lives each year** as well as prevent over 4,000 people a year from developing diabetes and detect at least 20,000 cases of diabetes or kidney disease earlier” (Public Health England 2016e; emphasis mine). Extrapolating from these metrics, Public Health England argued that the Health Check would allow “individuals to be better managed and improve their quality of life” (ibid.). The headline figures cited were based on the first economic modelling and subsequent consultation of the Health Check (Vascular Checks Programme, 2008), and have travelled in time, being cited in many policy and research papers since.

As the work of NCVIN and the Primary Care CVD Leadership Forum has developed, policymakers have increasingly focused on the financial savings to be made from CVD prevention work and used GBD knowledge to quantify these potential savings. Whereas, for instance, in 2013, policy drew predominantly on mortality data in order

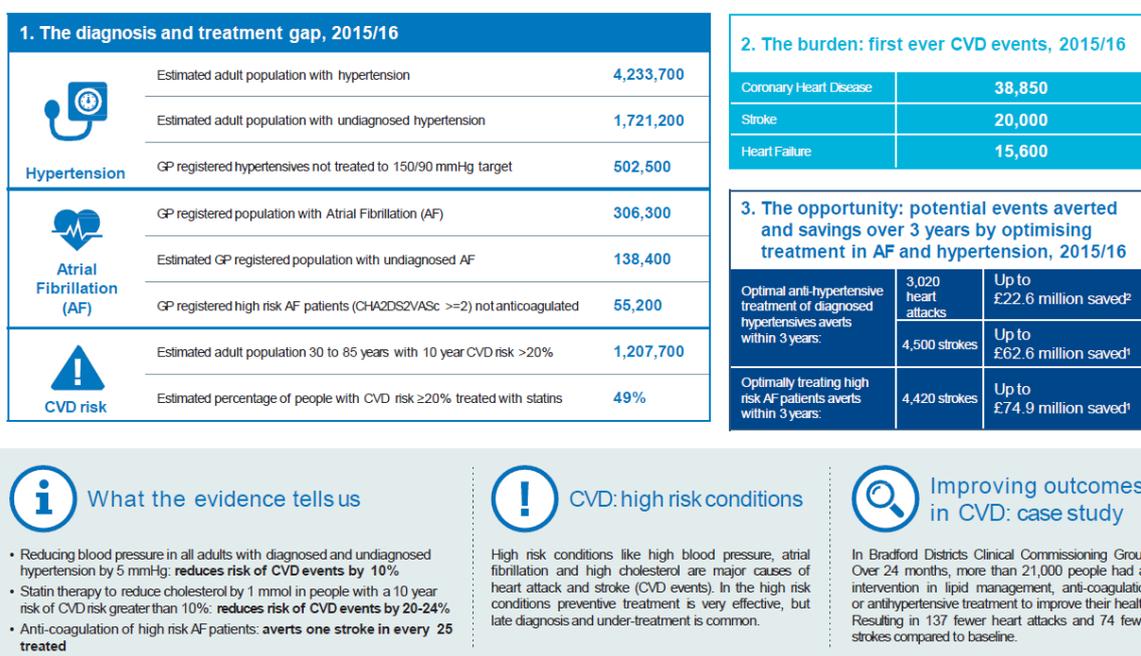
²⁷ Using QALYs gained, the cost-effectiveness of different interventions can be compared. As a rule, NICE funds interventions which cost less than £20,000 per QALY gained (NICE, 2012a).

²⁸ Although QALYs and DALYs are different measures (and include a slightly different approach to assessing ‘health related quality of life’) an inverted relationship is sufficient for the analysis presented here (see NCCID, 2015 for more details).

²⁹ Estimates of cost savings are built on calculations of ‘relative’ or ‘attributable’ risk (Optimix Matrix, 2014) (similar to the data on which GBD attributable fractions are also based (Lopez et al., 2006, p.245)).

to argue that “we know that taking action to address the big killers will bring benefits across the spectrum of ill health” (Department of Health, 2013c), in 2017 the ‘CVD prevention pathway’ (Kearney and Freeman, 2016) involved quantifying and publicising the projected cost savings from “high impact interventions” for each commissioning locality in England. These potential savings (and their associated health benefits) have been marketed to local managers more recently as ‘prizes’. An illustration of ‘Size of the Prize’ metrics for one region of England is shown at *Figure 9*.

The Size of the Prize in Cardiovascular Disease (CVD) Prevention Midlands and East of England



Footnotes:
¹ Royal College of Physicians (2016). Sentinel Stroke National Audit Programme: Cost and Cost-effectiveness analysis. Technical report
² Kear, M (2012). Chronic Kidney disease in England: The human and financial cost
 Potential events calculated with NNT (theNNT.com). For blood pressure, anti-hypertensive medicines for five years to prevent death, heart attacks, and strokes:
 1 in 100 for heart attack, 1 in 67 for stroke. For AF, warfarin over 1.5 years: 1 in 25 for stroke. Numbers may be lower, as some patients may be on prior treatment.

Figure 9: The Size of the Prize for an English region (NHS Health Check, 2017)

The logical rationality of ‘evidence based’ preventive interventions is thus presented by policymakers as a win-win strategy. On the one hand, patients benefit through saved lives and prevention of ill-health associated with CVD and its risk conditions. On the other hand the healthcare system saves money through reducing the financial burden of these chronic conditions — and the wider economy gains from economically active workers and consumers.

A full analysis and critique of the complex modelling simulations, their assumptions, and their predictions about the clinical and cost benefits to the healthcare system is

beyond the scope of this doctoral work. However, it is important to understand that the calculations behind the suite of interventions for CVD prevention (of ‘quality of life gained’, ‘cost-effectiveness’ and so on) are part of the same institutional complex, the same GBD ‘sphere of activity’ as the calculations of ‘burden of disease’ highlighted earlier in this chapter. As Adams points out, such metrics are generated using various “statistical tactics” which, in the case of QALYs and DALYs, “assign numerical values to expert perception of quality of life” and to life’s “potential economic productivity” (Adams, 2016, p.26,29). This highly-textualised, population health knowledge of people’s individual lives, built on multiple metrics and statistical algorithms, is utilised by policymakers to construct a population health story with a ‘happy ending’ — of both lives and costs saved.

In Chapter 1, I highlighted Dan’s story. In this chapter, I have shown that policymakers activating a GBD discourse tell another story to engage frontline HCPs and patients in GBD reasoning and practices. As I will show in the chapters that follow, patients’ stories and the stories told within the GBD discourse (and the forms of knowledge embedded in them) coalesce in frontline prevention work — even though terms such as ‘burden of disease’, ‘prevalence’, and ‘cost-effectiveness’ are rarely heard in the everyday interactions between HCPs and patients. However, as I showed in Chapter 1, the two forms of knowledge sometimes clash. Having provided a broad overview of the GBD discourse here, I continue to explicate how this knowledge enters into local CVD prevention knowledge and practices in the chapters which follow.

2.7 Organisational structures involved in CVD prevention

It is helpful, at the end of this chapter, to provide a very brief overview of the organisational structures involved in CVD prevention. *Figure 10* shows some of the major organisations involved, most of which do not explicitly appear in the accounts presented here. However, both Clinical Commissioning Groups (CCGs) and local authorities (LAs) play important roles in CVD prevention, and policymakers within these organisations were interviewed as part of the study, as well as HCPs and others working in frontline healthcare provision (see 3.8). The National Institute for Health and Care Excellence (NICE) also plays a crucial role in the social organisation of CVD prevention as it coordinates the production of evidence-based guidance and advice, the development of quality standards and performance

metrics, and the provision of information for commissioners and other policymakers (NICE, 2018b). Several participants in this study had been involved in these activities, in various capacities.

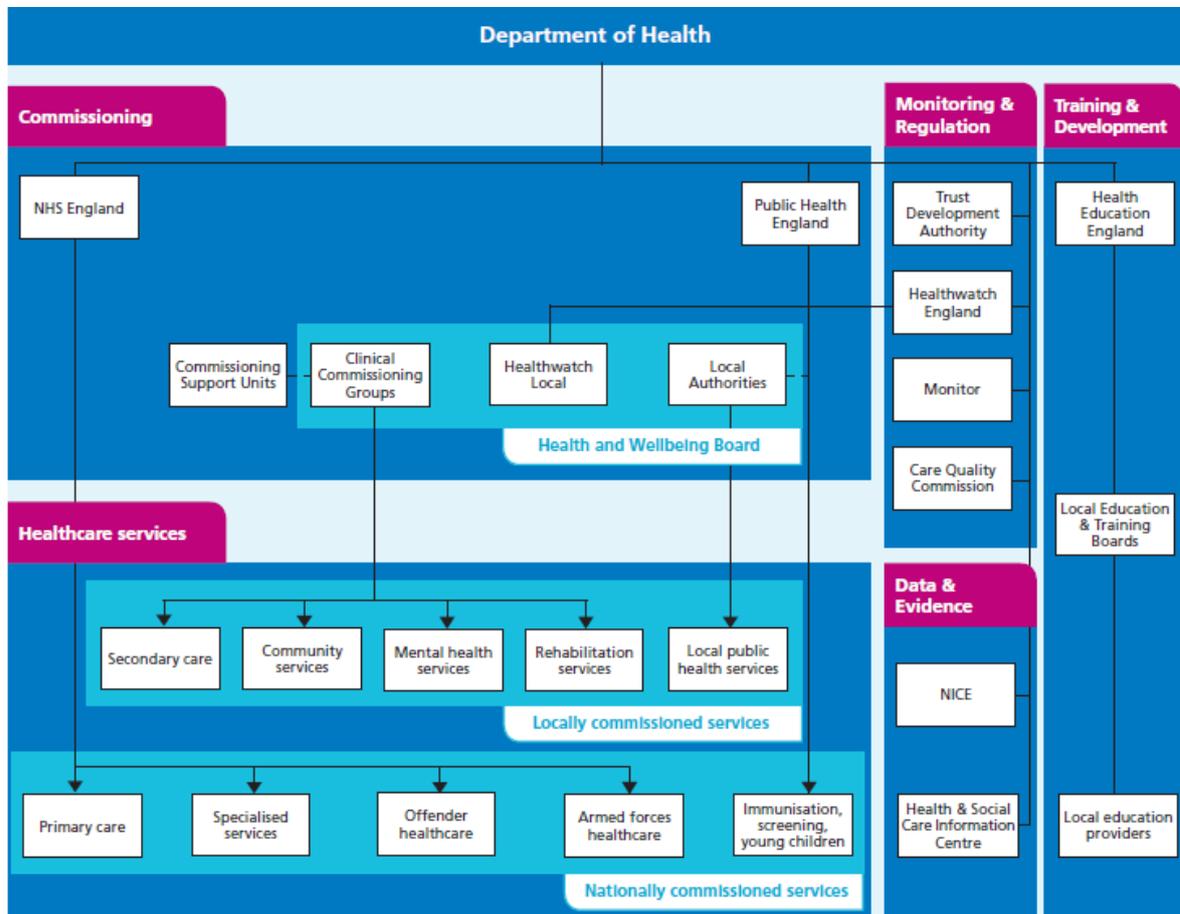


Figure 10: Structure of the NHS (NHS England, 2014b)

It is important to note here that healthcare services have been increasingly understood to have “a direct role in identifying people’s health needs and intervening early to address them” (The King’s Fund, 2017). As discussed in 2.1, policy has focused on the risk factors which are understood to be most ‘amenable’ to healthcare intervention and which will reduce the impact of not only CVD, but also other non-communicable diseases. The increasing range of interventions addressing CVD risk factors also dovetails with an increasing policy focus on the prevention and management of ‘chronic diseases’ (in some cases themselves also risk factors for CVD) in general practice. Changes to the GP contract in 2004 introduced “new mechanisms for supporting public health activity” through ‘Locally Enhanced Services’ and the ‘Quality and Outcomes Framework’ (QOF) (Peckham et al., 2011). The QOF is an important part of the institutional infrastructure

presented in this thesis. Described as the “largest health related pay-for-performance scheme in the world” (Roland and Guthrie, 2016), it incentivises general practice providers to actively identify, monitor, and manage chronic ‘diseases’, including the CVD risk conditions in *Figure 7*. As a result of the QOF, health centres conduct a systematised process of ‘reviewing’ patients who are diagnosed with the ‘chronic diseases’ included within the QOF. These reviews are guided by electronic templates, which have been found to very significantly shape HCPs’ work (see, for example, Diabetes.co.uk, 2018 for basic information on the tests covered in “diabetic reviews”; and Swinglehurst et al., 2012 for an ethnographic analysis). I return to an analysis of how QOF metrics enter into HCPs’ work in Chapter 8.

Within the institutional relations organising CVD prevention (as introduced in this chapter), ‘social and environmental’ risk factors (*Figure 1*) are positioned as more distal determinants of health, with a complex and less directly ‘causal’ relationship to CVD. My data indicate that GPs are often frustrated with the ‘social problems’ which inhibit their work (and sometimes with the lack of social support outside of healthcare services). These GPs daily witness the influence of wider social problems on their patients’ health and feel that they do not have the time or resources to adequately support patients experiencing diverse social difficulties (see, for example, Tomlinson, 2012); they point out that their role is hampered when issues associated with social determinants of health are not adequately addressed through social publicly-funded provision (e.g. Manek, 2017). Although professional bodies working in partnership with policymakers have emphasised the unique role of general practice in providing “person-centred coordinated care of complex physical, mental and social issues, within the context of the individual, their families and the wider community” (NHS England, 2016a), clinical guidelines continue to be orientated around a single-disease focus (Mangin and Heath, 2015). During the course of this study, general practice was also under particular strain, frequently described as being “in crisis” (Dayan et al., 2014; Roland and Everington, 2016). Although I do not dwell on the time constraints operating in general practice, problems of both funding, and recruiting, GPs form an important backdrop to this study.

Chapter 3 Entrée to the study, approach, and methods

In this chapter, I complete an overview of my approach to this study (which I began in Chapter 1) and provide details of the practical methods involved. I describe my entrée to this study of CVD prevention from within the academy and from listening to the concerns of activist clinicians working to challenge the status quo. These beginnings illustrate narratively how clinical-academic debates about the practice of medicine generally, and CVD prevention more specifically, are structured by conceptual ideas about ‘evidence-based medicine’. I include this entrée within this methods chapter because starting from this point was inevitably influential in my own knowledge (I return to these ideas in more detail in Chapter 4).

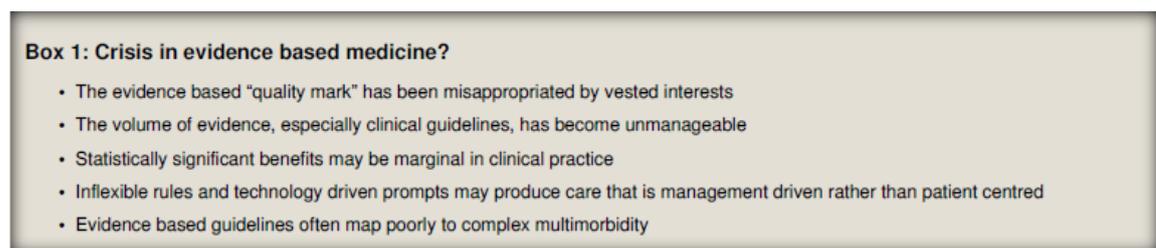
I then outline my reasons for employing institutional ethnography’s distinctive approach. I particularly focus on IE’s theoretical use of: ‘social relations’; ‘texts’; and ‘ideology’ — tools which I used extensively during data collection and analysis. Using the concept of ‘standpoint’ introduced in Chapter 1, I describe how I consciously shifted my own empirical ‘location’ in relation to the research, away from a location within the academy, to take a standpoint with patients experiencing preventive care. Smith’s activist concern is that this kind of research is *in the interests* of those whose standpoint it takes. When people (like Dan – see Chapter 1) are able to understand the social organisation of their own work, they may find an opportunity to “disrupt” or “escape” the authority of ruling relations (Smith, 2014, pp.249–250).

Lastly, I describe how I implemented an IE approach in practice. It was only at the end of my first year of PhD study that I specifically developed the study as an IE, with the “ontological shift” that this required (Smith, 2005b, p.123). The approach turned out to be particularly challenging, working without the local support of those using IE, and negotiating the differences (and the implications of those differences) between IE and more commonly used approaches to ethnography. Although IE has in some cases been presented as one of many different methods of ‘doing ethnography’ (Gobo, 2008), I discovered (gradually through the course of the study) that its attention to the social organisation of people’s knowledge fundamentally affected how I would collect, analyse, and

‘write-up’ ethnographic data, and contrasted with more commonly used, anthropologically-rooted ethnographic approaches (Campbell and Gregor, 2002) — and also with more applied forms of ethnography which have been employed to study healthcare and healthcare improvement (Dixon-Woods, 2003; Cupit et al., 2018). It was only through immersing myself in IE’s theoretical framework, and iteratively applying it to my data, that I was able to learn the approach. This learning was supported by advice from Janet Rankin, an experienced IE researcher with an interest in the social organisation of healthcare (Rankin and Campbell, 2006) and in the teaching of IE (Rankin, 2017a, 2017b), who agreed to act as a methodological advisor to the study.

3.1 Entrée to the study: from clinical and scholarly debate to an ethnography of CVD prevention

My interest in the issues covered by this study started with listening to the concerns of clinician-academics about potential ‘harms’ from CVD prevention. I was first introduced to these concerns as a result of reading what has become a seminal paper (published in the British Medical Journal), ‘Evidence Based Medicine: a movement in crisis’ (Greenhalgh et al., 2014). In their paper, Greenhalgh et al. contended that Evidence Based Medicine (EBM) had, following its rise as a “‘new paradigm’ for teaching and practising clinical medicine” (in the 1990s), become distorted and was now ‘in crisis’. They summarised these problems as in *Figure 11*.³⁰



Box 1: Crisis in evidence based medicine?

- The evidence based “quality mark” has been misappropriated by vested interests
- The volume of evidence, especially clinical guidelines, has become unmanageable
- Statistically significant benefits may be marginal in clinical practice
- Inflexible rules and technology driven prompts may produce care that is management driven rather than patient centred
- Evidence based guidelines often map poorly to complex multimorbidity

Figure 11: Summary of the ‘crisis in EBM’ from Greenhalgh et al. (2014)

Greenhalgh et al.’s paper drew examples from across the spectrum of healthcare — from disease prevention practices to the management of terminal illness. They

³⁰ *Figure 11* and *Figure 12* serve only as a very general guide to the concerns presented in the paper here.

highlighted that “evidence based guidelines may become irrelevant, absurd, or even harmful” in the care of an individual patient, and that the guidelines often promoted ‘overdiagnosis’, ‘overtreatment’ and ‘overscreening’. Particularly highlighting disease prevention practices, they claimed that EBM had “drifted [...] from investigating and managing established disease to detecting and intervening in non-diseases” — in other words, *even a population without identified disease* were vulnerable to intervention and thus the potential for iatrogenic harm as a result of some of the practices associated with EBM. The charges levelled at ‘distorted EBM’ were big and far-reaching. And the responsibility for taking action to address these concerns stretched across patients, clinical trainers, guideline developers, journal editors, policymakers, research funders – to name but a few.

The article promoted a new campaign for healthcare to return to ‘real EBM’ – which “has the care of individual patients as its top priority”, and asks “what is the best course of action for this patient, in these circumstances, at this point in their illness or condition?” A summary of Greenhalgh et al.’s description of ‘real EBM’ and proposed actions to achieve it are shown in *Figure 12*. Greenhalgh et al.’s views have been influential within the clinical/academic community, having been cited more than 800 times at the time of writing (August 2018).

Box 2: What is real evidence based medicine and how do we achieve it?

Real evidence based medicine:

- Makes the ethical care of the patient its top priority
- Demands individualised evidence in a format that clinicians and patients can understand
- Is characterised by expert judgment rather than mechanical rule following
- Shares decisions with patients through meaningful conversations
- Builds on a strong clinician-patient relationship and the human aspects of care
- Applies these principles at community level for evidence based public health

Actions to deliver real evidence based medicine

- Patients must demand better evidence, better presented, better explained, and applied in a more personalised way
- Clinical training must go beyond searching and critical appraisal to hone expert judgment and shared decision making skills
- Producers of evidence summaries, clinical guidelines, and decision support tools must take account of who will use them, for what purposes, and under what constraints
- Publishers must demand that studies meet usability standards as well as methodological ones
- Policy makers must resist the instrumental generation and use of “evidence” by vested interests
- Independent funders must increasingly shape the production, synthesis, and dissemination of high quality clinical and public health evidence
- The research agenda must become broader and more interdisciplinary, embracing the experience of illness, the psychology of evidence interpretation, the negotiation and sharing of evidence by clinicians and patients, and how to prevent harm from overdiagnosis

Figure 12: ‘Real EBM’ and how to achieve it (from Greenhalgh et al. (2014))

3.1.1 ‘Real EBM’: the ‘ideal model’

The drive to return to ‘real EBM’ refers back to EBM’s originating vision, often theoretically represented as consisting of three, complementary elements: research evidence; clinical expertise; and patient preferences (see *Figure 13*).

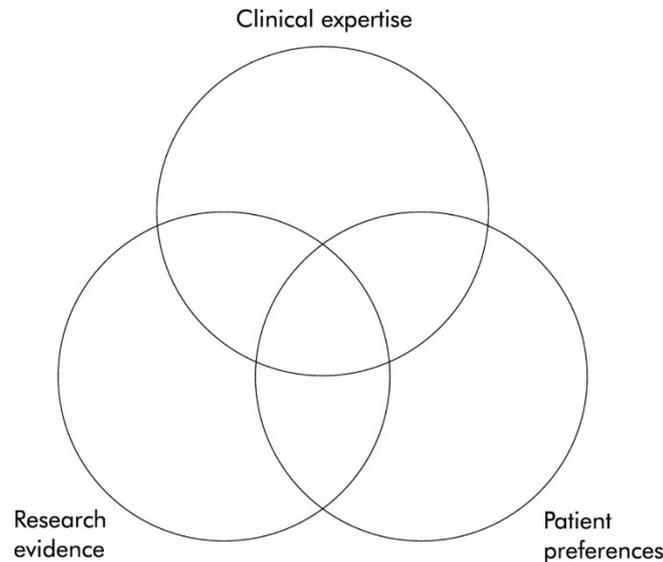


Figure 13 Model of the key elements for evidence-based clinical decisions from Sackett et al. (2000) (Haynes et al., 2002)

Within this schema, clinical guidelines (produced in the UK by the National Institute of Health and Care Excellence (NICE, 2018b)) summarise the best available research evidence for clinicians to then apply sensitively to an individual patient, taking into account their individual needs, circumstances, and preferences. Although EBM’s *raison d’être* and focus was always the implementation of ‘best evidence’ in clinical practice, the three elements have nonetheless been considered complementary. However, the 800+ citations from Greenhalgh’s paper suggest the extent to which EBM’s conceptual frame, and ideas about how this is applied in practice, have come under scrutiny. Even the chair of NICE has felt the need to reassert that “guidelines [should] not [be] tramlines” (McCartney et al., 2016) — that their role was only to *guide*, rather than to *constrain*, care practices — and to emphasise the limits of research evidence and guidelines.

3.1.2 “Too much medicine” and the ‘harms’ of CVD prevention

Greenhalgh et al.’s (2014) article introduced readers to a new Evidence Based Medicine Renaissance Group which had been set up to challenge the perceived

problems besetting EBM. On contacting Greenhalgh, she pointed me to an ‘Overdiagnosis Standing Group’ (‘Overdiagnosis Group’) which was being established within the RCGP as part of this work (McCartney and Treadwell, 2014). I attended its inaugural meeting in September 2014. The Overdiagnosis Group forms part of an increasingly prominent international ‘Preventing Overdiagnosis’ (POD) community, made up predominantly of GPs, and which held its first annual conference in 2013. This community is not only concerned with ‘overdiagnosis’ but more broadly with ‘too much medicine’ (Carter et al., 2015). Their aim is to advocate and promote ‘real EBM’ and to challenge the ways in which ‘distorted EBM’ promotes overdiagnosis and overtreatment — which risk generating more harm than good for some patients. Although NICE has emphasised that clinical guidelines should not be ‘tramlines’ (as above), GPs argue that institutional pressure to ‘follow’ them skews their work so that they cannot truly attend to patients’ values and preferences (be ‘patient-centred’ — see Chapter 8). They have raised particular concerns that younger generations of GPs are not equipped to adapt guidelines’ standardised recommendations to their patients’ needs and best interests. The group serves as a collegiate network for discussion and support and, through the online forum, I listened to their concerns.

The practices of CVD prevention were frequently discussed within the group during this study (see also McCartney’s (2012) critique of CVD and other prevention practices). Of particular concern has been the guideline recommendation to prescribe statins to patients above a calculated risk threshold (see Chapter 7), a topic which was hotly debated in prominent medical journals during the course of my research. This debate focused on how the evidence of benefits and side-effects of statins should be interpreted, and potential biases in its production. Concerns about CVD prevention practices however were about more than just statin medications: speculated ‘harms’ of CVD prevention are illustrated in *Figure 14*. (This word-cloud was produced to capture some of the concerns expressed on the forum — presented here, with permission.)



Figure 14: ‘Harms’ of CVD prevention (Treadwell, 2017)

In Chapter 4, I return to consider dominant clinical-academic discourses which frame CVD prevention, including the ‘harms’ proposed in *Figure 14* — which range from very specific clinical problems (e.g. ‘side-effects’ of medications) to more abstract ideas, influenced by psychological and sociological understandings (e.g. ‘fear’; ‘disease labelling’). Whatever the perceived ‘causes’ of ‘too much medicine’ (e.g. the distortion of evidence through the influence of the pharmaceutical industry (“vested interests”) (Greenhalgh et al., 2014; Carter et al., 2015)), practical solutions put forward within the POD community have rested largely on implementing ‘shared decision-making’ (SDM) as an ethical and pragmatic frame to guide practices. This approach is reflected in the Overdiagnosis Group’s strapline, “for shared decisions in healthcare”.

Before moving onto the theoretical approach and practical methods involved in this study, some brief background to SDM is useful here, as the concept emerges at various points throughout this analysis. SDM has been described as “a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences”, and policymakers have for some time aspired to incorporate this model into medical practice (Coulter and Collins, 2011). A ‘shared decision’ is one in which an HCP supports a patient to make an informed choice about alternative treatment options — where multiple “reasonable options” exist (Elwyn and Durand, 2017) or the decision is “preference sensitive” (Politi et al.,

2013). Arising originally as novel and challenging to traditional clinical practice (e.g. Elwyn et al., 1999), the SDM model has become increasingly, albeit slowly, integrated into policymaking, being rhetorically established in policy since the government white paper ‘Equity and Excellence’ (Department of Health, 2010). Delays incorporating SDM have sometimes been attributed to “system inertia and paternalism” (Richards et al., 2015). (I return to a discussion of ‘paternalism’ in Chapter 9.) Campaigners for more (and ‘better’) SDM advocate the use of ‘decision-aids’ which provide information on the relative statistical benefits and harms of particular treatments³¹, and which HCPs can use with patients to support them in making decisions aligned with their “values and preferences” (e.g. NICE, 2014i). At the time of this study, a number of different individuals and organisations were developing such tools to support SDM.

3.1.3 From debates about CVD prevention to an ethnographic study

My aim in the previous sections has been to provide a brief narrative overview of my “scholarly” entrée to the field of CVD prevention (Campbell and Gregor, 2002, p.17) and, in particular, the debate around ‘overdiagnosis’ and ‘too much medicine’. Naturally, as I listened to the concerns of the Preventing Overdiagnosis movement, I also reviewed established CVD prevention policy and research literature to which the debate related (see below and Chapter 4). On the one hand, the case (in policy and guidelines) for addressing CVD risk factors/conditions appeared clear and incontrovertible. On the other hand, debates about both the research evidence itself, and the application of that evidence in frontline practice, disrupted and added multiple complexities to that simple view. Even when there was general consensus about the clinical evidence for a particular intervention (e.g. the benefits of antihypertensive medications for high blood pressure) many questions remained. For instance, did this evidence apply equally to all patients? What about some groups who were more likely to experience side-effects? What about the potential for harm such as ‘falls’ in the elderly? What about people who were only just over the threshold of a hypertension diagnosis? How effective could ‘lifestyle’ change be in treating hypertension? And how long should HCPs *wait* for patients to attempt ‘lifestyle

³¹ Sometimes presented as ‘number needed to treat’ (NNT) or ‘number needed to harm’ (NNH).

change'? What about people with other conditions or with social problems such as drug addiction, housing crisis? The list of questions (and the complexity to which they pointed) went on.

As discussed above, SDM was proffered by those both inside and outside of the POD movement as a way of overcoming the difficulties of applying clinical guidelines in the treatment of individuals. Indeed, SDM was positioned as being *inherent* to proposed notions of 'real EBM'; 'harms' which the POD community associated with CVD prevention (see *Figure 14*) were largely attributed to poor application of SDM in practice. However, as I read the academic literature and listened to these contemporary debates, I questioned the adequacy of EBM (and its related concepts such as SDM) to depict and respond to the tensions which HCPs reported in their CVD prevention practices. It was also impossible to 'see' from these representations how they were implemented (or not) in practice.

Ethnography provides a 'way of seeing' (Wolcott, 2008; Smith, 1987) which has been employed in the study of healthcare and healthcare improvement, and which "[queries] understandings and practices that are taken for granted" and is able to "[probe] into areas where measurement is not easy" (Dixon-Woods, 2003). Additionally Savage (2006) has argued that, due to its broad scope, attention to context, and mission to give voice to individual experience, ethnography can also provide "a counter for the totalising tendencies of evidence-based practice" and a way of "exploring the concept of evidence itself, or the interaction of different kinds of evidence, within the various contexts in which evidence-based practice is promoted". Ethnographic studies have, notably, shed light on the processes by which clinical guidelines are applied in English general practice (Gabbay and May, 2004; Swinglehurst et al., 2012). The practices of CVD prevention in England have not however (to my knowledge) been studied ethnographically, although some ethnographic research has described, for example, the practices of people diagnosed with diabetes (Hinder and Greenhalgh, 2012) or heart disease (Wheatley, 2006). Other studies have used qualitative methods to explore the views and experiences of those receiving or delivering particular elements of preventive care (see Chapter 4). This study therefore contributes new knowledge about CVD prevention by looking at what *actually happens*.

I chose to apply an institutional ethnographic approach as it provided a well-developed theoretical framework for interrogating the adequacy of prevailing concepts — as laid out in key IE methodological texts (e.g. Campbell and Gregor, 2002; Smith, 2006c). Fundamental to IE is that the research “must avoid applying topical [...] theoretical formulations circulating about the issues under investigation [...] that activate a prior theoretical framework and distract the researcher from being able to describe and examine what people actually do” (Rankin, 2017a). Similar to many other ethnographic approaches, IE investigates people’s actual, material practices. However, its explicit and focused attention on the ways in which conceptual framings are themselves *part of the ‘social organisation’* of these practices resonated with my early observations of the academic field. In light of my misgivings about circulating concepts relating to CVD prevention³², IE offered an “alternative sociology” (Smith, 2005b) which dared to unpick even the theories of sociology itself. In addition, institutional ethnography looks beyond a local setting to discover *why* and *how* things happen as they do. This was particularly pertinent for studying healthcare practices which are increasingly determined, not only by the individual skills and expertise of those whose work can be seen at the frontline, but also by policies, guidelines, and other management devices developed *away* from the frontline. In the following section, I provide a more detailed overview of the IE approach.

3.2 Institutional ethnography: discovering social organisation

This study was conducted in line with core principles of IE inquiry as outlined in key methodological texts (e.g. Smith, 2005b, 2006c; Campbell and Gregor, 2002). IE’s approach involves many terms which (although also employed in other approaches) refer to distinct analytical concepts in IE. In Chapter 1, I introduced some of these key concepts which included: different ‘kinds of knowledge’; the ‘problematic’; ‘work’; ‘standpoint’; and ‘social organisation’. I briefly illustrated these in relation to Dan’s story. The concept of ‘discourse’ was

³² EBM and SDM were particularly dominant but there were many other conceptual representations.

introduced in Chapter 2. For readers unfamiliar with IE, useful glossaries of analytic terms have been produced by Smith (2005b) and Bisailon (2012).

Here, I emphasise the concept of ‘social relations’ (which is directly linked to ‘social organisation’), and also outline very briefly the importance of IE’s theoretical construction of ‘texts’ and ‘ideology’. Uncovering social relations and, more specifically, how these relations are coordinated (or ‘organised’) institutionally is the central aim of IE. The relevance of this theoretical approach relates back to Smith’s experiences in the ‘women’s movement’ during the 1970s in which she found that “the sociology [she] learned and that organised the cognitive domain of [her] work at the university defined and interpreted the world of home and family, but there was no talking back” (Smith, 1987, p.8). In other words, she could only interpret and talk about her work as a mother using categories and concepts which “decentred” her experience (ibid.). These were ‘ruling’ concepts that, although not adequately reflecting her everyday work as a mother and academic, coordinated her and others’ work from a distance. The approach she developed, now described as IE, was one that would allow her, and others, to ‘talk back’ to the ‘relations of ruling’ in which people are ‘objects’ (objectified) — spoken *about* but not *from* the located, embodied particularities of their everyday worlds (their ‘standpoint’ — see Chapter 1).

In order to talk back to these relations, Smith (2005b, p.38) explains that “[institutional] ethnography may start by exploring the experience of those directly involved in the institutional setting, but they are not the objects of investigation”. IE’s “theory of knowledge” is that knowledge “relates us to others in a specific way” (Campbell and Gregor, 2002, p.15) — one person’s location in relation to institutional relations of power is different to another’s. For instance, Dan’s position in relation to relations of power is different to his GP’s, and his GP’s is different to a local healthcare commissioner’s. All of these people’s *activities* are ‘socially organised’ (“concerted and coordinated purposefully” (Campbell and Gregor, 2002, p.27)), and so too is their *knowledge* about how to act. In fact, using IE’s ontology, *knowledge* is *enacted*. IE’s mission therefore is to explore how people’s activity (what they do) is underpinned by their knowledge. Ultimately the goal is to describe and explicate how knowledge enters into and coordinates people’s work (and the problems associated with that work) across different times

and locations. Unlike some other research methods, its primary goal is not to investigate a setting (a particular physical location) ethnographically, and produce descriptions (theorised or otherwise) of ‘culture’ or ‘context’ (see below).

As described in Chapter 1, I took a standpoint with patients, and started to investigate their knowledge of the “actualities of [their] everyday lives and experience” in order to then direct attention to how their knowledge and experiences were socially organised from beyond the local setting — to “discover the social as it extends beyond experience” (Smith, 2005b, p.10). Taking a standpoint is a tool that provides a way for the researcher to examine how the people being studied (those whose standpoint the researcher has taken) are institutionally positioned. The standpoint ontologically grounds the researcher to people and their work. This is different to many contemporary approaches to ethnography within medical settings. In these approaches, ethnographers have frequently adopted an identity — e.g. doctor, visitor or patient (Galasiński, 2011) and recognised their ‘situatedness’ using tools of ‘reflexivity’ (Clifford and Marcus, 1986), but they have tended to stop short of aligning themselves with the interests of a group, preferring instead a more ‘neutral’ voice. In IE by contrast, taking a standpoint positions the researcher as working *in the interests* of that group. It does not necessitate that they are a member of the standpoint group (although this is often the case), or attempt to ‘walk in the shoes’ of the standpoint position, but it does mean that they are “committed to knowing on behalf of those whose lives [they study]” (Campbell and Gregor, 2002, p.48). A standpoint is not to be confused with research on ‘patient experience’ (often consumer-focused feelings of satisfaction or dissatisfaction, or emotional responses to illness or healthcare practices) — although these feelings are naturally involved.

Here, my focus is on “discovering how things are put together” (Smith, 2006a, p.1) — by mapping social relations from the standpoint location (Campbell and Gregor, 2002). **‘SOCIAL RELATIONS’ (or ‘organisation’)** “refers to the coordinating of people’s activities on a large scale, as this occurs in and across multiple sites, involving the activities of people who are not known to each other and who do not meet face-to-face” (DeVault and McCoy, 2006, p.17). Where social relations appear to have a suppressive effect, they are alternatively described as ‘ruling relations’. IE’s ontology develops a different stance towards

power and governance from those developed through Foucauldian analyses (see, for example Smith, 2014). Ruling relations in IE are empirical; they are ‘activated’ by people (all of us) who are organised to *participate* in ruling practices; for instance people take up and apply prominent discourses or carry out textual processes that insert ruling knowledge and directs their practices. This study then is of the social organisation of patients’ efforts to improve their health, and particularly as their ‘work’ (using IE’s “generous concept of work” (Campbell and Gregor, 2002, p.72) — see Chapter 1) intersects with the formal structures of preventive care delivered in general practice.

Finally (in this brief introduction to IE), it is important to emphasise the methodological importance of textual analysis, and the concept of ‘ideology’. Investigating social relations involves exploring the ways in which people activate ‘**TEXTS**’ — “material objects that carry messages” — that are “reproduced many times so that people can read the same text in different places or at different times” (Smith and Turner, 2014, p.5). Crucial to IE’s study of texts is that they enter into, and coordinate, people’s activities in sequences of action (Figure 15).

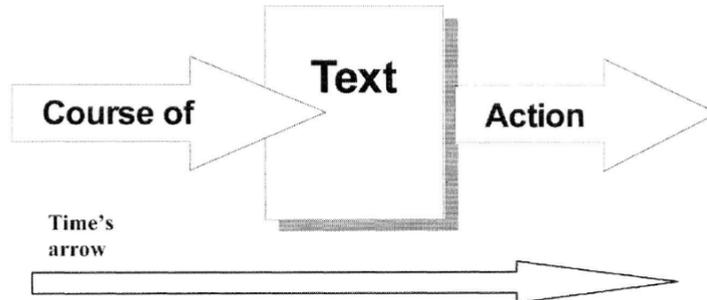


Figure 15: Conceptualising texts in action (the Act-Text-Act sequence) from Smith (2006b, p.67)

Texts are crucially important in both creating aggregate representations about people and situations (e.g. in research publications), and then applying these standardised forms of knowledge back into their everyday lives (e.g. in clinical guidelines). When Dan’s GP talks with him, for instance, about taking anticoagulants to treat his atrial fibrillation, she activates a textual knowledge of the clinical guideline and applies it to Dan’s situation. Using IE terms, ruling relations are ‘textually-mediated’. The GP knows from the guideline and the research evidence that lies behind it, that Dan should take this medication. Dan

however receives the guideline's text through the GP, but he reads it differently. He brings his own knowledge of his situation, of potential side-effects, of previous experiences of taking medications. Their different knowledges collide as they are located differently in relation to institutional relations of power.

Smith develops her use of the concept of '**IDEOLOGY**' from Marx and Engels, whilst distancing herself from the political connotations which their work evokes (Smith, 1987, 2005b; Bisailon and Rankin, 2012). She explains that ideology consists of "ideas and social forms of consciousness [which] originate outside experience, coming from an external source and becoming a forced set of categories into which we must stuff the awkward and resistant actualities of our worlds" (Smith, 1987, p.55). These ideological and authoritative categories "may dominate and perpetuate the social consciousness of the society in general, and thus may effectively control the social process of consciousness in ways that deny expression to the actual experience people have in the working relations of their everyday world" (ibid.) This knowledge (or 'consciousness') is always a part of people's *practices* — knowledge and practice cannot be separated — or in Smith's words, "participation in the 'head' world is accomplished in actual concrete settings making use of definite material means" (ibid., p.85). When people act according to an institutional knowledge which is at odds with their (or others') local, embodied experience, this can be described as 'ideological practice'. Ideological practices then are "coordinated by the textually organised relations of ruling" which subordinate everyday experiences by creating an alternative, ideological accounts of those experiences (Griffith, 2006, p.137).

Ideological knowledge and practice are frequently transported through the institutional employment of "shell terms" (Smith, 2005b, p.112) which stand in for people's real activities. In this thesis, I show how prevention is rife with such terms, which carry all kinds of meanings and may be activated differently in different situations — but whose *practices* may be frequently left unexamined. Smith says that these terms are "waiting for the reader to fill them with substance extracted from the local actualities of her or his work" (ibid., p.113). Drawing on these theoretical ideas, Rankin and Campbell (2006, p.126) provide an example of how ideological language is frequently "blended" with more local / natural understandings. In their study, the word 'quality' (ibid. p.143) was used differently

in the local setting to how it was activated in a *managerial setting*, where it was used to coordinate ruling practices. In the managers' mouths, the term 'quality' subsumed (but also *depended on*) its local use in mouths of nurses. Rankin and Campbell show how ruling relations, embedded in particular language use, depend on people assuming a shared (blended and ideological) meaning that leaves local knowledge behind.

In 3.1, I outlined the origins of this study which included ideas about avoiding 'harm' to patients. 'Doing no harm' is a foundational building block of medical practice (Sokol, 2013), and is increasingly discussed as part of contemporary analyses of the quality and safety of healthcare (see, for example, Vincent, 2010). I highlighted that members of the Preventing Overdiagnosis (POD) movement proposed that, contrary to the popular view of preventive practices as innocuous, they could cause 'harm'. Dominant hypotheses of harm within this movement included those from 'disease labelling' (e.g. psychological effects causing anxiety / fear), and 'side-effects' of medications (e.g. 'falls' in elderly people taking antihypertensives, and 'polypharmacy' (see also 4.4.4). The IE approach taken in this study takes a different tack to analyses which employ abstracted definitions or conceptions such as 'harm', 'overdiagnosis' or 'SDM'. Instead, it foregrounds what actually happens and the practices of prevention are described and examined as empirical matters.

I want to highlight one other aspect of the IE use of 'ideology' here. In the following extract, Smith (2005b, p.54) notes that the concept enables what is sometimes called 'culture' to be empirically examined.

*"I view the ideas, images, and symbols in which our experience is given social form not as that neutral floating thing called culture but as what is actually produced by specialists and by people who are part of the apparatus by which the ruling class maintains its control over the society. Thus, the concept of **ideology provides us with a thread through the maze different from our more familiar notions of "culture"**, for it directs us to look for and at the actual practical organisation of the production of images, ideas, symbols, concepts, vocabularies, as means for us to think about our world. It directs us to examine who produces what for whom, where the social forms of consciousness come from." (Emphasis mine)*

The utility of ethnography for shedding light on institutional ‘culture’ (understood as “shared meanings, beliefs, practices, rituals, ceremonies, stories and material artefacts that are represented in, and are reproduced by, social life” (Waring and Jones, 2016)) is increasingly being recognised as important in healthcare improvement work (see, for example, Dixon-Woods, 2003; Savage, 2006). The IE approach, and particularly the concept of ideology, points the researcher to *practices* (“who produces what for whom” (2005b, p.54)) and provides a way of exploring *why* particular problems consistently happen (described as ‘culture’ in some ethnographic approaches). By making *connections between the local and the translocal*, the amorphous “floating thing called culture” (as above) can be empirically investigated, and particular aspects of it identified as the product of ruling relations. This approach stands in contrast to methods of data analysis which are frequently employed in qualitative research, which focus on the production of ‘themes’ (frequently employing the use of shell terms) from which theoretical understandings are developed, or on which they are superimposed. Such thematic approaches to data analysis “lose [the data’s] meaning as situated activity” and may therefore be particularly prone to perpetuating ideological understandings (Campbell and Gregor, 2002, p.69).

This thesis could be considered to be an ethnographic ‘tour’ of the social organisation of CVD prevention. The terrain is huge, and so I select carefully, following “threads” (DeVault and McCoy, 2006, p.24) which help to explicate the problems I discovered. I draw on a wide range of different data sources, including observations in general practice, interviews with patients and frontline HCPs, readings of policy and research literature “as data”, and wider ethnographic observations including attending conferences and following discussions about CVD prevention on Twitter. In the remainder of this chapter, I detail how I applied IE’s approach to this study.

3.3 Sensitising notions of ‘health work’

As discussed in 1.2 and 3.2 above, the notion of ‘work’ is integral to an IE analysis. IE researchers have used the notion of ‘health work’ to loosely “direct [their] attention toward the wide range of practices that people engage in around their health without defining in advance what that work might or should involve” (Mykhalovskiy and McCoy, 2002). In this sense, IE healthcare researchers

(especially those taking a patient standpoint) share the concern of other researchers who have highlighted that an increasing amount, and new forms, of work are falling to patients within contemporary healthcare systems. In this section, I very briefly outline some of the scholarly approaches to understanding patients' work that resonated with my interest in what patients are doing, and consider how my design of this IE study is positioned to contribute something distinctive to that broader discourse.

3.3.1 'Burden of treatment'

Patients' 'health work' has been called the "burden of treatment" (e.g. May et al., 2014; Mair and May, 2014), alternatively defined as the "workload of healthcare and its impact on patient functioning and well-being" (Eton et al., 2013). Examples of the work involved include (but are not limited to) side effects of treatments, collecting and monitoring clinical data, and navigating the healthcare system. Such work may involve extensive time, effort, and intellectual / educational resources (Mair and May, 2014). The work, or burden, of treatment has been found to be particularly troublesome when multiple treatments for multiple conditions are recommended for an individual patient (i.e. in cases of 'multimorbidity').

'Burden of treatment theory' draws on a hybrid of other theories and models, from which related calls for "minimally disruptive medicine" have emerged (May et al., 2009a; Leppin et al., 2015).³³ Important within the 'burden of treatment' approach is that an individual's capacity to take on healthcare work is not only a property of the individual but also depends on "their relational networks, social skill [...] and social capital" (May et al., 2014). This refocusing away from the individual, towards a patient's social environment and their "capabilities" to "self-care" and "live well", has also been highlighted by other researchers (e.g. Entwistle and Watt, 2013; Entwistle and Cribb, 2013). The notions of burden of treatment and capability have been useful in highlighting the work which patients almost inevitably take on following diagnosis of a chronic disease, and the daily

³³ Theoretical influences on 'burden of treatment' model include: Normalisation Process Theory (May et al., 2009b); the Cumulative Complexity Model (Shippee et al., 2012); and phenomenological "lived body" approaches (e.g. Pickard and Rogers, 2012) — see May et al. (2014).

challenges of living with that disease. Although ideas about the burden of treatment are more frequently employed in analyses of complex multimorbidity, these ideas also have relevance for preventive work, particularly when it involves pharmaceutical intervention for which there may be a ‘burden’ from side-effects of medications as well as the act of taking them (Yudkin and Montori, 2014).

3.3.2 ‘Logic of care’

Another stream of research, which directly speaks to the notion of ‘health work’, comes out of the field of Science and Technology Studies (STS). Annemarie Mol opens up the notion of ‘care’ for scrutiny (see, in particular, Mol, 2008; Mol et al., 2010), an orientation which proved particularly useful as I developed the problematic of this study. Her interests in people’s concerted efforts — described by Mol and other scholars as care ‘*practices*’ — aligned with the concerns I was uncovering in relation to ‘preventive care’, and the IE concept of work. Through detailed ethnographic analyses of people’s work (particularly focusing on management of diabetes), Mol (2008) “disentangles” care practices “from an all too immediate association with kindness, dedication and generosity” (p5) arguing that, although these are crucial to care, this conception often casts care work in an oppositional relationship to the multiple forms of technology which enter into people’s work.³⁴ Instead, she highlights the many benefits of biomedical (and other) technologies, and argues that caring practices inevitably *include* them, contending both that technology can shape people’s work, and that people can in turn work creatively with technology.

Mol poses questions about what ‘good care’ looks like in practice, and provides some contingent answers. A key part of her analyses is contrasting practices which she associates with a ‘logic of care’, with practices associated with a ‘logic of choice’. Within the logic of choice, dominant understandings of patients as ‘consumers’ or ‘citizens’ (who exercise individual autonomy over a sequence of one-off, rational decisions) are activated, and this framing is understood to

³⁴ ‘Technology’ is not defined in Mol’s work but includes a range of non-human actors and processes. This is similar to IE’s attention to technologies, which are textual and thereby standardising in nature (see, for example, Rankin and Campbell, 2006). In my study, although I do not necessarily always describe them as such, technologies include: preventive medications; blood tests; lifestyle education programmes; the NHS Health Check programme; risk scoring algorithms; design of clinical trials; and many other aspects of preventive practice.

challenge an outdated model of professional ‘paternalism’. Within the logic of care, by contrast, professionals involve patients in an ongoing process of care based on their individual ‘needs’ — choices are ‘practical tasks’ which, although needing to be undertaken, are part of this continuing process. As loosely defined sets of practices, Mol argues that the logic of care has a broad coherence which she aims to articulate, and to make visible. Mol et al. (2010) describe her aim, and the aim of others working in the same field, as being to “strengthen care practices — and whoever is involved in them”. Although she refuses to formally define (to “cast in stone”) ‘good care’ or the ‘logic of care’ (Mol, 2008, p.95; Mol et al., 2011), she continually points to her characterisation of it — describing care, for instance, as “a calm, persistent but forgiving effort to improve the situation of a patient, or to keep this from deteriorating” (Mol, 2008, p.23) or as “tinkering with bodies, technologies and knowledge” (Mol, 2008, p.14). ‘Bad care’ is when people are being “ignored” or “neglected” (Mol, 2008, p.97). This characterisation of ‘good care’, she argues, is a “good place to start” as it “takes [people] seriously as [they] are, disease and all” (Mol, 2008, p.96). In my study, my “place to start” was with individual patients and the problems that were “real to them” (see Chapter 1). My reading of Mol’s work sensitised how I listened to these accounts and how I perceived the problems people (often indirectly) talked about. Although I utilised IE’s ontological framework in this study (not Actor Network Theory on which Mol draws)³⁵, I briefly outline below some particular aspects of Mol’s work which I found useful.

First, her detailed analyses of care practices open up the *individualised, local and compromising nature* of care work — both care provided by professionals and ‘self-care’. Highlighting the unpredictable or “unruly” nature of people’s bodies, she exposes good care practices as being adaptive to the many unattractive aspects of managing chronic disease and the many compromises which have to be made. It is her conception of “tinkering” on which I particularly draw. Management of blood glucose, for instance, may require regular, ongoing adjustment, experimentation, and “meticulous attention” to the “unpredictabilities of bodies” (Mol, 2008, p.14). Good care, she argues is antithetical to universal

³⁵ In fact, Mol argues that ANT is not a theory (Mol, 2010).

principles. Instead people engage in good care when they work out “local solutions to specific problems” which, in practice, will involve “seeking a compromise between different ‘goods’” — i.e. different, perhaps conflicting, good outcomes (Mol et al., 2010, p.13).

Mol highlights a dimension of analysis often missing within healthcare research – that a compromise between different, sometimes clashing, sometimes unpalatable outcomes is frequently required. For instance, a person taking insulin for diabetes may want to adhere to guideline recommendations about blood glucose levels, but they may also want to avoid having a ‘hypo’ (which can be caused by too much insulin). As many others have also noted, the measures of success explored in clinical trials do not necessarily correspond with the goals of patients and HCPs — “if there are different treatments, the question is not just which of them is more effective, but also which effects are more desirable” (Mol, 2008, p.54). Dan’s story in the Chapter 1 exemplifies this observation. Mol elevates care practices in which people work inventively with technologies and claims that “categories are adaptable” (Mol, 2008, p.76) — see below. In the end, Mol observes, compromise is inevitable. After all, “you do your best, but you are not going to live ‘ever after’” (ibid.). Good care sometimes can only serve to make life more bearable in the face of inevitable morbidity and mortality.

Second, and crucial to my analytical use of her ideas, Mol’s descriptions of ‘good care’ and ‘bad care’ resonated with the accounts of standpoint informants in my study. In Chapter 5, I will introduce Naomi. Her account is filled with illustrations of what Mol might describe as ‘neglect’. Like Mol’s participants, Naomi described (in her own words) how her “personal experiences were not attended to” and how she “would have appreciated more support”. As Mol describes, “a hole opens up and you fear that you will fall right through it” (Mol, 2008, p.97), that “nobody cares”. There is “nobody who is interested in their experiences with uncertainty, fear, shame, loneliness and the never-ending pressure of having to take care of themselves” (p.98). Mol’s work highlights the aspects of care which are often invisible and/or considered unimportant in authoritative understandings — the relevance of finding it difficult to “get through on the flippin phone” (interview with Naomi) to her ability to be supported with problems arising with her medication, for instance. As Mol says, “such small wonders do not show up in population

statistics” (Mol, 2008, p.81). However, these (often invisible) aspects of practice make up the ‘logic of care’, a ‘style’ of working which is “under threat” because it “does not speak for itself” (Mol, 2008, p.2) and is not elevated in dominant ways of knowing about healthcare.

Third (and related to the previous points), Mol foregrounds care as an *ongoing process* in which both HCPs and patients are involved. Care may include the technologies of short-term ‘interventions’, but these are not the sum of care. She writes, “the logic of choice suggests that choosing is confined to specific moments. Privileged moments, difficult maybe, but bounded. The logic of care, by contrast, suggests that attuning the many viscous variables of a life to each other is a continuing process. It goes on and on, until the day you die” (Mol, 2008, p.62). As I listened to informant accounts, Mol’s work sensitised me to some of the problems people faced as they struggled to make their prevention work ‘fit’ into their everyday (ongoing) lives (see Chapter 1) as, simultaneously, they were confronted with “situations of choice” (ibid., p.74) for which they were ill-equipped. Although each standpoint informant experienced unique problems, a desire for these to be recognised, to be taken account of, by HCPs brought coherence to these accounts.

I have briefly outlined some of the ways in which I found Mol’s analyses relevant to the tensions I identified that led to the analysis I conducted. There is important congruence in her descriptions of care practices to the data amassed for this study. I also found many elements of her ontological approach to complement IE’s. For example, similarly to Smith’s emphasis on avoiding ideological conceptualisations, Mol argues (in Mol et al., 2011) that it is important to keep influential conceptual framings at bay, arguing that such framings will “kill your curiosity before you have learned anything new”. In this spirit, and similar to IE, her ‘logics’ are not posed as theoretical formulations but as useful holders to characterise different approaches to practice. Although such elements of complementarity are important (and ANT and IE share some common ground, for instance in their focus on practices (Corman and Barron, 2017)), I have not attempted to merge Mol’s theoretical ideas, or those of ANT (in which Mol’s analyses are grounded), with the IE approach.

As in IE, Mol's work is orientated towards local practices; however she does not move beyond these to *empirically study, and show, the social organisation of people's local work practices*.³⁶ It is here that this study diverges from Mol's analyses. The IE approach involves moving beyond local practices to uncover their social organisation — and, in particular, how people's knowledge of how to perform is socially organised in a material way that activates ruling discourses (often mediated through texts). It is in IE's detailed attention to explicating the social organisation of knowledge that my work also diverges from other work which draws on Mol's ideas or Actor Network Theory.³⁷ Whereas Mol sees in her ethnographic data a complex of intermingling practices, texts, technologies and the like, I specifically look for material traces of ruling relations in that mix and, where applicable, emphasise their ruling power over people's activities. However, Mol's work informs the topic and the IE approach to enquiry; I show that it is therefore often very difficult for HCPs and others to contextually “tinker” with bodies, technologies and knowledge. Nonetheless as Mol describes, I discovered that it *can, with commitment, strategem and subversion* sometimes be achieved.

3.4 Study governance

This study was approved by an NHS Research Ethics Committee (REF: 15/NW/0883) which reviewed the processes and documentation to be used during the study (e.g. consent processes, use of participant data).

3.5 Collecting and analysing data: an overview

This study is centred on observations at two general practices (known here as Wildwood Health Centre and Riverbank Health Centre) and on interviews with

³⁶ She does however continually gesture to the power structures coordinating those practices (for example, highlighting the influences of epidemiological research methods, the categorisations used in clinical practice, and population statistics (Mol, 2008)).

³⁷ See, for comparison, Henwood et al.'s (2011) study of people's accounts of 'healthy living'. They describe how the logic of choice enters into participants' accounts and argue that the logic of choice is “disciplining” (i.e. that, although participants sometimes challenged the logic of choice, their understandings were still shaped within its logic). An IE however would find material traces of social organisation in participant accounts and empirically investigate how these arose — e.g. how a specific ‘situations of choice’ came about.

patients.³⁸ These were supplemented with interviews with HCPs (and some administrative staff) based both at these health centres and at other sites, and with other participants who, although not active at the frontline, were nonetheless able to provide insight into the social relations organising patients' health improvement work. A summary of data collection is presented at Figure 16. This also includes ethnographic data collection completed throughout the study. Guides to formal participants and their positions within institutional relations are shown at Appendix 1 ('standpoint informants') and Appendix 2 ('extra-local informants').³⁹ Interviews were audio-recorded and transcribed. I took brief fieldnotes during observations, supplementing these immediately following observation with details which I had not been able to note down at the time.

³⁸ All names of participants and locations are pseudonymised. Descriptive details are sometimes omitted or changed to protect the identities of participants and those associated with them, where I did not consider that doing so would adversely impact the integrity of the study.

³⁹ The analytical distinction between 'standpoint informants' and 'extra-local informants' is described by Bisailon and Rankin (2012). Of course, these categories overlapped.

	Wildwood	Riverbank	Other	Total
TOTAL Participants	15	8	30	53
Standpoint informants	8	3	13	24
Extra-local informants ⁴⁰	7	5	17	29
TOTAL Observation of clinical practice (hours)	17	15		32
Healthcare Assistant	4	11		
Practice Nurse	6	4		
GP	7			
Examples of other ethnographic data collection (unquantified hours) ⁴¹	<ul style="list-style-type: none"> • Motivational interviewing training day • Issues and Answers in Cardiovascular Disease conference • Following national CVD leaders and other policymakers / commentators on Twitter • Following news stories / policy updates about CVD prevention • Reading policy and research literature 			

Figure 16: Summary of formal data collection showing where participants were recruited, and formal clinical observation time

Analysis ran iteratively throughout the study, as I formulated (and reformulated) a problematic, sketched out sequences of action, ‘indexed’ preliminary findings, wrote pieces of analysis in “chunks” (Rankin, 2017a), and periodically discussed with Janet Rankin, who was advising methodologically. I found that articulating the problematic as a highly focused single statement was challenging as there was no single episode or question which seemed to encapsulate the disparate, but somehow similar, tensions patients faced. I continued a process of defining and refining the problematic throughout the study, increasingly focusing on the

⁴⁰ Six participants participated by being both observed and interviewed, and are therefore counted twice.

⁴¹ I include a wide range of activities here in accordance with IE’s focus on “literature [and other textual materials] as data” (Rankin, 2017a).

preventive interactions between patients and HCPs — for instance, moments in which patients were working to generate constructive relationships with HCPs to support them with improving their health, but in which HCPs seemed unable or unwilling to respond, or moments in which patients' aspirations for health were at odds with official conceptions (as in Dan's story). In order to explicate the problematic, DeVault and McCoy (2006, p.24) contend that "the process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out". However, it "doesn't have to progress in orderly and distinct stages", particularly "when the researcher already has a good working knowledge of the institutional field" (McCoy, 2006, p.124). I had accumulated some knowledge of the field and also, for pragmatic reasons, the process of interviewing standpoint and extra-local informants overlapped. I also found that the ruling relations organising CVD prevention were "sprawling, sometimes tangled webs of text and activity" (Devault, 2006) and therefore I saw many traces of the social organisation of HCPs' and patients' work which presented many different potential 'threads' to follow. Although in this thesis I focus on one main thread, which led to global health metrics (see Chapter 2), I gesture towards many other threads partially explored, and to the complexity involved in ethnographically understanding the practices of preventive care.

Distinguishing IE from many other qualitative and ethnographic approaches is that "the research goal is to empirically link, describe, and explicate tensions embedded in people's practices not to theorise them" (Rankin, 2017a) (see 3.2). In this sense, IE "finds an uneasy fit with research approaches interested in studying 'qualitative' phenomena" as these "have established techniques to abstract from data with explicit goals to develop theory, interpretations, or 'meanings'" (Rankin, 2017b). In my description of methods below, I pay particular attention to the methodological work involved in producing an analysis which would avoid my own "**INSTITUTIONAL CAPTURE**"⁴² (Smith, 2005b, p.155) by dominant discourses — which claim to 'know' patients' health improvement work. This happens when people (research participants, researchers, or others) draw on institutional discourse to displace their own, or others', experiences, and is a

⁴² Sometimes also described as 'ideological capture'.

central concern of IE. Smith has highlighted that institutional capture happens particularly when both informant and researcher are familiar with the institutional discourse and share its common ideas embedded in language (see Chapter 4). The knowledge of CVD prevention embedded in frontline practices was rife with prevailing conceptualisations (e.g. ‘motivation’, ‘informed choice’, ‘adherence’) which present opportunities to “gloss-over” or “leave out” important elements of people’s everyday work (Rankin, 2017b).

As a researcher, it is easy to pick up and use the ideological frames which appear both in academic and policy texts, and in informants’ accounts. Campbell and Gregor (2002, p.71) have noted that informants, particularly those who work as part of formalised institutional structures, often talk in language which is dominated by such ideological frames; they describe this tendency as providing “professional accounts”. In collecting and analysing data for this study, I was guided by their advice that “the test of whether you are getting a professional account as opposed to an account of what actually happened is if you, the listener, cannot see every step without having to imagine pieces” (ibid., p.77). My collection and analysis of data was directed by this requirement to ‘fill in the gaps’ in people’s accounts by investigating the material actions involved, rather than accepting ideological accounts; this approach mitigated against missing crucially important aspects of patients’ accounts (see, for instance, Galasiński, 2011 for a critique of ethnography which is carried out from a “ruling” perspective).⁴³ It involved systematic and detailed analysis of people’s accounts in order to ensure analytic attention to people’s *work* (using IE’s generous definition) and how it was orientated to institutional relations; their work was frequently not clear during first readings of interview transcripts. ‘Indexing’ using NVivo qualitative data management software (“organising data into linked practices and happenings”) (Rankin, 2017b) and writing short pieces of analysis supported this approach.

⁴³ This is not a ‘failsafe’ approach. Rankin notes the difficulty in avoiding institutional capture. I provide a brief illustration of the inevitability of using institutional concepts and priorities in 5.2 below.

3.6 Health centres

I selected Wildwood and Riverbank health centres opportunistically, based on their positive response to my invitation to participate.⁴⁴ During exploratory discussions, several HCPs at each site also expressed willingness to be observed. The health centres differed considerably in population demographic, Riverbank being situated in a provincial village/town with low levels of deprivation, and Wildwood being a city suburban area with very high levels of deprivation.⁴⁵ Wildwood had approximately 15,000 registered patients; Riverbank had approximately 10,000. They were in different commissioning areas (English-Town CCG, and English-County CCG) but, from a patient standpoint at least, many aspects of service provision would have appeared very similar.⁴⁶ Both had expanded their registered list of patients and were actively investigating ways of reorganising their services to meet increased demand. Wildwood, for instance, was considering whether they might close their registered list to new patients in response to “unprecedented pressure from rising workload, tightening budgets, and widespread staff shortages” (Lind, 2017).

I observed 32 hours of clinical practice, mostly with HCAs carrying out NHS Health Checks (and other interspersed appointments), but also with Practice Nurses delivering chronic disease management checks, and with a GP in routine consultation. No patients objected to my presence: as HCPs pointed out, many were familiar with trainees observing. I attempted to maintain a friendly ‘background’ presence throughout these consultations although, at times, either HCP or patient involved me, e.g. patients sometimes asked about my study, or told me about their symptoms. A high blood pressure reading was sometimes jokingly attributed to my presence, prior to being re-checked.

⁴⁴ I telephoned health centres from a list provided by the Clinical Research Network.

⁴⁵ Riverbank was in decile 7 Local Layer Super Output Area (LSOA) with surrounding areas in deciles 8 and 9. Wildwood was in decile 4, with surrounding areas in deciles 1-8. Wildwood predominantly served patients living in deciles 1 and 2. Deprivation data was sourced using Indices of Multiple Deprivation mapping tool <http://dclgapps.communities.gov.uk/imd/idmap.html>.

⁴⁶ Clinical care is standardised nationally through clinical guidelines. Although provision varies according to local commissioning arrangements, the overall types and format of services appeared relatively uniform across commissioning areas.

3.7 Standpoint informants

I recruited standpoint informants through a variety of approaches including posters/leaflets in the reception areas of participating health centres, social media (Facebook), and advertising/networking in the local community. An example poster used in the waiting area of participating health centres is shown at Figure 17.

RESEARCH STUDY
RISK-I (Exploring RISK-Identification to prevent cardiovascular disease)

My name is Caroline Morris and I am a postgraduate research student at the University of Leicester. I am organising a research study which will look at how this practice finds people who are most at risk of heart attack and stroke – and helps to prevent this.

What will I be doing?

1. **Observing** what happens in the practice. It is possible that I may be observing when you come for an appointment.
Patients are FREE TO OPT OUT OF THIS – NO QUESTIONS ASKED.
2. **Talking to patients** about their experiences of being ‘at risk’ and about their preventative care. You may receive a letter to ask you to be involved, or you can contact me direct (more information below).



CAN YOU HELP? I’d like to talk to you

I will be talking to people aged between 18 and 84 who could be categorised as being ‘at risk’ because of one, or more, of the following:

high cholesterol	diabetes / pre-diabetes	high blood pressure
age 40+	high alcohol consumption	weight problems
smoking habits	low exercise levels	unbalanced diet

“I’m not looking for ‘model patients’ – I’m interested in listening to your experiences – and what you find difficult or problematic”

Caroline Morris, Researcher

What will the conversation be like?
 I will talk to you informally about how you do (or don’t) manage your risk . It is not anticipated to take more than 45 mins.

What if I’m not interested in monitoring these risk factors?
 That’s fine. I will not be telling you what you should/or shouldn’t be doing.

Where will it be?
 You can let me know when / where would be best for you, but could be your home, or in a private room at the practice if available.

Will my information be confidential?
 All discussions in interviews will be kept confidential and nothing which identifies you personally will be discussed with anyone in the practice.

For more information, collect information and reply slip from reception, or contact Caroline Morris directly at cm582@le.ac.uk or 07816 329 848. University of Leicester
POSTER V1 RISK-I (20151014)

Figure 17: Poster displayed in participating health centres⁴⁷

I specifically sought out participants who were from more economically deprived situations, appreciating that their voices are often omitted from research (Smith,

⁴⁷ I changed my surname since undertaking data collection in health centres.

1987; Martin et al., 2015), or are aggregated within authoritative categories such as ‘hard to reach’ groups (see for example, Liljas et al. (2017)). In line with IE’s approach, the demographic and other data in Appendix 1 (either provided by the informant, or deduced from information supplied) were not intended for the purpose of categorical analysis as in some research methods, and are not validated as technically ‘accurate’, but rather helped me to appreciate the circumstances of people’s lives, how their needs were understood within healthcare practice, and the issues they faced in relation to improving their health. These data also demonstrate that I have sought “informants who can report on varied circumstances and situations” (DeVault and McCoy, 2006, p.32).

In order to recruit patients who might often be excluded from research studies, I met with a community centre manager who invited me to attend a ‘coffee morning’ at the centre – an approach described by Martin et al. (2015) as research “in the wild”. From that meeting, I recruited four participants who would have been unlikely to respond to a formal research invitation. Several others were interested in the study but (although clearly encouraged by the £10 shopping voucher available for participants) appeared distrustful and declined.⁴⁸ My interview with Naomi forms the basis of Chapter 5 and, along with other informants recruited at the community centre, became central to my analysis. Their accounts oriented me, for instance, as I met with extra-local informants to consider ‘how does their account fit with what I have heard from Naomi (and others)?’ (i.e. from the standpoint location). As CVD is known to be much more prevalent in more deprived communities, and voices from these communities are frequently not included in research (Pandya, 2014), it was important to me that individuals from these communities were given prominence in my study.

My commitment to including a wide range of standpoint informants presented various challenges and, in particular, as I looked to refine and explicate a problematic. As Campbell and Gregor (2002, p.95) point out, “not all stories seem

⁴⁸ The community centre manager had warned me that I might not get any interest in the study due to concerns in the community about providing information which could affect their welfare benefits. Many members of the community were on disability benefits, he said, and these were crucial to being able to pay rent and for basic necessities. Anyone from outside the community he said might be viewed with suspicion.

to be pointing in the same direction” — the accounts I was hearing from deprived circumstances were filled with different experiences and concerns to many others of my informants. For instance, standardised CVD prevention practices (e.g. managing blood pressure to a target level) entered into Naomi’s and Philip’s work differently. Although these differences related in part to differences in their individual bodies, they were also due to the cultural, social and financial resources which each had at their disposal. However, I found that “different stories [enlarged my] overall understanding of what [was] happening” (ibid.). By continuing to focus on the *social organisation* of patients’ work, I could understand these different patient accounts not just as “differing *perspectives*” (with a focus on the perceiver) from different social contexts, but also as “*positioned* differently” within social relations (Campbell and Gregor, 2002, p.65); the social organisation of people’s knowledge remains the empirical focus of the research.

Of the 24 standpoint informants, I talked with 15 at their home, three at a community centre, five over the phone, and one by Skype. Interviews lasted 30-70 minutes and were loosely structured around patients’ preventive work, particularly the management of ‘risk factors’ as outlined in policy and guidance (see Figure 17).⁴⁹ I took particular care to ensure that patients understood that I was not judging them, or their situations, and allowed our conversation to focus on their own particular concerns. Applying IE’s (feminist) concern with challenging authoritative language which distorts people’s accounts, I recognised that “most members of a society learn to interpret their experiences in terms of dominant language and meanings” and that therefore I would need to “interview in ways that [allowed] the exploration of incompletely articulated aspects of [people’s] experiences.” (Devault, 1990). In patients’ accounts, I looked for what Smith describes as ‘**DISJUNCTURES**’ — gaps between what they knew from an experiential perspective and what they knew from a ruling perspective. For instance, in Naomi’s account (Chapter 5), I did not uncritically accept her frequent reiteration that she was ‘unmotivated’, or understand this as simply her ‘perspective’. Rather, her own categorisation of herself (clearly drawn from her

⁴⁹ In interviews, I did not use the term ‘work’ - which has been found to be problematic in other studies. (Mykhalovskiy and McCoy 2002; MacGregor and Wathen 2014).

interactions with HCPs as well as from more generalised understandings) could be seen to show traces of the institutional relations entering into her experience, which were in tension with her account of the material realities of her life.

During interviews, I guided participants to tell me about elements of their experience which linked them with institutional relations, following IE's "ontological commitment of staying focused on the material conditions of people's lives, including their textual and other practices" (Bisaillon and Rankin, 2012). As Mol (2008, p.11) has similarly argued, interviewing about practices rather than opinions "[extends] ethnographic observation" and took me where I "had no time or license to go". However, it was challenging as it required persistent nudging to prevent interviews going "off track" (Bisaillon and Rankin, 2012). In line with Bisaillon and Rankin's experience of interviewing, patients appeared to expect that I would be most interested in their "inner emotive experiences", rather than the "*connections* between the personal, social, and political worlds [they] inhabit". I frequently had to interrupt with what appeared to be 'technical' questions about the institutional processes into which they had been drawn, and in which they sometimes had little interest; these were boring and technocratic to them. However, I found that, by being focused and astute about when and how to interrupt the flow of conversation, I was able to facilitate patients' narrative accounts whilst also gathering the more process-orientated information required for this type of study.

3.8 Extra-local informants

I purposively recruited 29 extra-local informants who would be able to help 'map' institutionally organised CVD prevention practices. A guide to these participants is shown in Appendix 2.⁵⁰ Most worked in frontline clinical practice. Some were involved in local healthcare management, either working for the Clinical Commissioning Group or for the Local Authority (Public Health division). Several had both clinical and other roles e.g. practising as both GP and academic, or taking on additional work on, for instance, a Guideline Development Group. All

⁵⁰ Details of informants' roles are deliberately limited in Appendices 1 and 2 to protect anonymity. However, additional key information about informants is provided throughout this thesis, where this is relevant to the analysis.

the GPs interviewed were ‘GP partners’ (i.e. financially invested in, and responsible for, the management of their health centre). I recruited six informants through the RCGP Overdiagnosis Group based on comments posted on the online forum, which had particular relevance to the ‘threads’ I was following. Many of these provided invaluable ‘background’ to the arguments I present here — a sense of the ‘bigger picture’ into which my explication (of particular aspects of the social organisation of CVD prevention) fits.

Selecting which extra-local informants to interview was based on my curiosity to uncover institutional processes of which I had discovered traces in previous interviews and observations — and which appeared analytically important for explicating the problematic. However, this was not a simple, or linear, process. In an IE, it is not possible to know immediately which threads to follow (DeVault and McCoy, 2006) and, although my enquiry was, in principle, disciplined by the problematic (Campbell and Gregor, 2002), I found that this evolved over time (3.5). As I progressed data collection, I began to focus on the Health Check programme. The Health Check was prominent in CVD prevention policy, being positioned as bringing multiple CVD prevention activities together, and providing the gateway to a suite of further interventions (2.6 and see also Figure 20). Although most patient informants had not recently (or ever) attended a dedicated Health Check appointment, they had experienced many of its constituent elements delivered in routine clinical consultation. For instance, they had received dietary advice or had been identified with ‘risk conditions’ such as hypertension, as a result of similar processes to those embedded in the Health Check. In order to recruit extra-local informants who would be able to shed light on the social organisation of Health Checks, I utilised professional contacts within the CCG who were able to point me to those involved in commissioning or managing the Health Check programme. I approached these individuals personally, as identified through professional networks.

Interviews with extra-local informants focused on how their “social location [informed their] knowing”, and “what [they could] say from this position” (Bisaillon and Rankin, 2012). As in patient interviews, I was particularly “attentive to the ideological forms and conventions of informants’ speech” because, as Bisaillon and Rankin describe, “resident in their language were important analytic traces

of the ways in which their thinking was discursively organised”. For instance, when informants talked about patients’ ‘lifestyles’, they mixed everyday language with ideological frames for a particular set of health improvement activities (3.5). A ‘healthy lifestyle’ frequently referred to particular standardised recommendations for diet and exercise, and abstaining from ‘unhealthy’ habits such as smoking, or drinking over a recommended amount of alcohol. Other aspects of the pattern of a patient’s life, which might be included within a more everyday conception of ‘lifestyle’ (e.g. social activities, relationships), had little apparent relevance within this interpretive frame. By recognising nominal forms of language such as ‘lifestyle’ as “shell terms” (Smith, 2005a, p.112) (see 3.2), I was able to analyse how they enter into, and organise, HCPs’ and patients’ everyday work.

As discussed earlier in this chapter, HCPs and academics frequently pointed to the impact of clinical guidelines on frontline practices, and it was clear from observations and interviews that (as expected) these did indeed play an important organising role. However, as IE and many other researchers have found, guidelines are a prominent, but only small part of the social organisation of healthcare (e.g. Mansfield, 1995; Mykhalovskiy and Weir, 2004). Following threads from informant accounts led me to see debates about EBM and clinical guidelines as being within a bigger global health discourse (see Chapter 2), of which clinical guidelines were only a part. Rather than focusing on the application of clinical guidelines (or EBM), I pulled out a thread which led to the wider management imperatives and performance metrics shaping HCPs’ (and patients’) work.

3.9 Research, policy and grey literature as carrying discourse

IE’s terrain for investigation is not limited to data captured in formal observations of frontline work, or in informant interviews, but rather involves studying the ways in which knowledge about that frontline work is constructed in authoritative representations such as in discourse and texts — produced away from the frontline, but present in the activities of frontline workers. For this reason, research literature is reviewed as data in IE (Rankin, 2017a).

My review of academic and policy literature was continuous and iterative. Appendix 3 lists some key policy documents which have governed CVD prevention in recent years, and on which I have drawn in this study. I discovered these policies through frequent web searches for topics arising in observations and interviews, following contemporary discussions (e.g. on Twitter and the Overdiagnosis Group forum), and talking with people and attending conferences (e.g. 'Issues and Answers in Cardiovascular Disease' 2016). I spent a considerable amount of time following 'clues' from one document to another. For example, I investigated the origins of the headline statement that the Health Check programme would "prevent 1,600 heart attacks and strokes and save at least 650 lives each year" (Public Health England, 2016e), which led me to an earlier economic model (Department of Health, 2008a), itself referencing many other texts. Clinical guidelines such as that for 'lipid modification' (NICE, 2014f) were saturated with textual knowledge from research studies which was to be applied by HCPs to patients' everyday lives.⁵¹ When I interviewed a Health Check programme manager, his references to encouraging better performance from health centres delivering the checks led me to service specifications detailing how these were funded and performance-managed.

In Chapter 4, rather than producing a conventional literature review, I outline some of the dominant 'ways of knowing' (standardised and prevalent discourses) which were important during this study. These are the kind of discourses on which frontline HCPs and patients draw — the discourses which allow patients' health improvement work to be known by HCPs and managers — but which, to use IE's ontology, "speak about [patients' work] one way, while [patients] on the ground speak about it another" (Campbell and Gregor, 2002, p.52). Throughout my reading, I applied IE's approach of maintaining a standpoint position in relation to the literature. How did the literature 'speak' about patients' work? And how did this align with patients' (and HCPs') accounts of their work?

⁵¹ For example, an HCP may 'know' (from reading the above guideline) that an individual weighing 60kg will expend 69Kcal of energy if they carry out 'light intensity' ironing for 30 minutes.

3.10 Summary

IE conforms neither to general understandings of ‘qualitative research’ in healthcare, nor with the theoretical practices of sociological study. Starting from problems which are ‘real’ to patients, I follow clues into the social organisation of knowledge which shapes those problems, including into debate about EBM, overdiagnosis and so on. I use the theoretical tools of IE in preference to other theoretical devices (such as ‘thematic analysis’ and ‘triangulation’) which may be more familiar to readers. IE instead relies on building an ‘account’ of institutional practices. As a result, I present data excerpts from only a limited number of informants, although my analysis takes account of a much broader body of data. At points, readers familiar with the diversity of health centres’ practices may wonder whether I am failing to recognise the breadth of HCPs’ (and patients’) practices. However, capturing diversity is not the main aim of this thesis. Instead I aim to explicate the tensions experienced by patients and HCPs working to prevent CVD. Instead of producing generalisations of patients’ or HCPs’ differing practices, I highlight ways in which ruling relations have generalising effects on these practices.

This chapter has provided an overview of how I practically applied IE’s ontology. This was not a smooth ride as I found the IE approach to rapidly expand the potential terrain of the study. Accordingly, I followed many more threads (and collected considerably more data) than I use in this study’s analysis; I have barely used data from interviews which focused on processes of research dissemination or guideline development, for instance.⁵² A slowly-clarified problematic contributed to this large amount of data as I discussed earlier in the chapter. Nonetheless, I argue that, as a result of taking IE’s ontological approach, the findings presented here contribute a different and important view, and that IE has potential to contribute to debates about the value and application of ethnography in the study of healthcare and healthcare improvement (Cupit et al., 2018).

⁵² However these contributed significantly to my understanding of the ‘bigger picture’ of the social organisation of CVD prevention practices.

3.11 Notes on terminology

I employ a considerable number of clinical, technical, managerial and theoretical terms in this thesis. As I introduce them, I attempt to provide adequate definition or explanation for the reader, without distracting from the flow of the argument. Where relevant, I include references. The term ‘patient’ is particularly troublesome as this thesis is about *prevention* of CVD; in many cases, the people encouraged to undertake preventive work are ‘healthy’ members of the public who only infrequently visit their health centre — in other words, they are not yet ‘patients’. However, for consistency, I use the term ‘patient’ loosely. Similarly, terms such as ‘policymakers’ and ‘activists’ are also used to loosely identify groups of actors involved in preventive care practices.

Chapter 4 How should CVD risk be managed in clinical practice? A review of policy and literature

This chapter documents a dominant ‘risk management’ discourse in CVD prevention policy and research literature — a relatively standardised form of knowledge (Smith, 2014, p.231), which is threaded through policy, and to which healthcare managers, healthcare professionals, and patients referred, either directly or indirectly, as authoritative (I discussed the IE use of the term ‘discourse’ in 2.3.1). My IE formulation of the ‘literature review’ focuses on the interventions which are authoritatively known to prevent CVD or, in other words, to ‘reduce risk’. It follows from my introduction, in Chapter 2, to how CVD prevention is based on epidemiological knowledge of risk factors within the population. Using the IE approach to analysis, I described this standardised knowledge about the impact of CVD risk factors as “knowledge for taking action” (Rankin and Campbell, 2006, p.7). I then outlined how certain authorised forms of action are positioned in policy as involving multiple stakeholders (commissioners, managers, frontline HCPs, patients etc.) in “reducing avoidable premature mortality” (Department of Health, 2013c) and, more broadly, a technical construction of the ‘burden of disease’ in both health and financial terms. The GBD ‘story’ told by policymakers is that the suite of interventions for CVD prevention will help patients ‘avoid disease’ and will ‘save lives’. In this chapter, I present the discursive practices of ‘risk management’ as part of this overarching GBD discourse. These practices are *specifically orientated* to delivering the suite of interventions previously introduced (see *Figure 6* and *Figure 7*).

This overview of risk management interventions (and the debates about them) underlines how interventions are textually standardised, and how they are linked to the practices of biomedicine, sometimes also represented as ‘evidence based medicine’ (EBM) — see 2.6/3.1. I focus on the *dominant* representations of CVD prevention among variously-positioned promoters and readers of the CVD discourse; the knowledge and debates I cover here represent only a small slice of the broad reading that has engaged me throughout this study. Instead, I stay closely focused on discourse that I can empirically link to the analysis developed in the chapters that follow. The analysis here is likewise rooted in ethnographic

observations and interviews, and in broader clinical discussion online e.g. RCGP Overdiagnosis Group. I draw on policy and research literature reviewed iteratively throughout the study, and follow IE's ontological commitment to discovering the social organisation of knowledge (see Chapter 3). A list of policy documents which particularly relate to CVD prevention are listed at Appendix 3 for reference. I particularly highlight the authoritative knowledge which is presented in guidelines, as these are widely understood to summarise the best available evidence of good practice (McColl et al., 1998; Greenhalgh et al., 2015; Treadwell, 2015); in my data from HCPs, they also emerged as a prominent form of clinical knowledge. For ease of presentation, I group interventions into three main categories: lifestyle interventions; medical treatment; and the NHS Health Check programme.⁵³ In addition, I highlight the role of digital risk scoring technology within the Health Check programme.

Although policymakers and frontline HCPs more commonly describe the knowledge practices I am calling 'risk management' using the term 'prevention', I use 'risk management' here because it better reflects the knowledge embedded in this discourse. As I describe in the following chapters, frontline HCPs consistently draw on the concept of risk management when they talk to their patients about needing to "reduce [their] risk" (EX27) — it dominates their knowledge of both "how to speak" (Smith, 2014, p.230) and how to act in relation to patients' health needs. Patients too sometimes "participate in" or "appropriate" this institutional discourse (McCoy, 2006, p.119) (see 2.3.1), but it is not their natural language; the discursive practices of 'risk management' frequently generate disjuncture between what Smith (2005b, p.187) describes as the "artificial realities of institutions and the actualities that people live". Many other conceptual ideas intersect with 'risk management'. As Morden (2012) has outlined, risk and risk management are integral to concepts of, for example, individual 'self-management' in UK policy; I do not therefore differentiate such ideas as separate 'discourses'. There are also many other 'voices' which speak about CVD prevention, variously positioned in relation to dominant understandings — debates arise as these different voices interact. Although I

⁵³ In line with World Health Organisation (2016) understandings of health 'interventions'.

focus on clinical-academic debate, I also include footnotes on the more prominent sociological discourses which speak about the topics covered in this review, to which I briefly return in Chapter 9, and which will be of particular interest to readers whose own knowledge is shaped by these discourses.

4.1 Lifestyle interventions

Individual ‘lifestyle’ or ‘behaviour’ change is considered to be the first-line approach to managing CVD risk⁵⁴ (NICE, 2014f, 2015b); a range of clinical guidelines instruct HCPs about how to offer advice and information.⁵⁵ These specifically address ‘lifestyle’ risk factors, such as: smoking; excess alcohol consumption; unhealthy diet; low physical activity; and obesity (see, for example,

⁵⁴ As I highlighted in Chapter 2, the concept of risk (and risk factors) within healthcare, and society more generally, is not unproblematic. Some authors have criticised the dominance of risk’s interpretive frame within both sociology and medicine (variously describing it as “risk thinking” (Rose, 1998), a “risk epidemic” (Skolbekken, 1995) or the “lens of risk” (Heyman, 2013)). Its dominance however has given rise to studies of the ‘sociology of risk’, along with related fields focusing on, for example, ‘uncertainty’ and ‘diagnosis’ which have to some extent influenced thinking about CVD and its risk factors (e.g. Zinn, 2008; Aronowitz, 2009). As Jutel and Nettleton (2011) highlight, “diagnostic categories [have become] less bounded, with the dualism of disease and non-disease collapsing in the face of new categorisations of potential disease and risk factors”. Analyses of the social construction of risk, uncertainty, and disease have highlighted, at the local level, “new preventative practices” (Aronowitz, 2009) and shed light on how people’s experiences are shaped by, for instance, new (quasi) diagnostic categorisations (Hindhede, 2014; Jutel, 2006) or risk technologies (Saukko et al., 2012). These critical social science analysts have tended to focus on how HCPs and patients ‘understand’, ‘communicate’ or ‘make sense’ of risk or disease (e.g. Hindhede, 2014; Jovanovic, 2014; Kreiner and Hunt, 2014; Alaszewski and Horlick-Jones, 2003; Eborall and Will, 2011) — in IE terms, the mental processing ‘work’ involved as well as the more visible work involved in undertaking lifestyle changes, attending healthcare appointments, and taking preventive medications. May et al. (2014) have more explicitly used a concept of ‘work’ to highlight the ‘work of patient-hood’. Although this concept has not specifically been applied to disease prevention, the ‘work’ associated with patients’ self-management of chronic conditions (e.g. Eton et al., 2012) has started to gain recognition within healthcare.

⁵⁵ In the sociological literature, an emphasis on individual ‘lifestyle’ has been associated with the ‘New Public Health’, in which “health [becomes] a matter of negotiation with ‘risk’” (Petersen and Wilkinson, 2007, p.4). Individuals being subject to the ideas of the New Public Health are understood to be both powerful in controlling their own destiny and also paradoxically vulnerable in the face of ever-present risks (Petersen and Wilkinson, 2007). The “regulated freedom” of citizenship promoted by neoliberal forms of rule gives individuals the right to welfare, but also the responsibility for diligently promoting their own health (Petersen and Lupton, 1996, p.xiii) — they are “active consumers rather than passive patients” (Alaszewski, 2009). Drawing on such Foucaultian influenced analyses, some authors have emphasised the “responsibilisation” of individuals and the associated moralistic “victim blaming” or “stigmatisation” associated with the New Public Health — shown to be a particular characteristic of health promotion (‘lifestyle’) discourse (Hansen and Easthope, 2007) which positions individuals as primarily responsible for health problems such as obesity. Critics argue that these individual ‘lifestyle’ issues are more appropriately addressed through social/environmental determinants and that focusing on individual responsibility detracts from a focus on wider social and political action (e.g. Korp, 2010; Baum, 2016).

NICE, 2011a, 2013, 2018a, 2014g, 2014h). These risk factors are understood to be constituents of ‘unhealthy lifestyles’ (NICE, 2014f) but to be ‘modifiable’ through ‘optimal management’. According to Boyce (2010), “providing advice and information is one of the primary ways GPs and other HCPs carry out public health and ill-health prevention”, and is delivered as part of GP contracts for provision of general medical services (Boyce et al., 2010; NHS Employers, 2016a).

Provision of information is foundational to guidelines, with HCPs currently directed to provide information in line with the NHS Choices website (e.g. NHS Choices, 2018c) — although NICE has itself remarked on the need for more research on how educational/informational material should be presented to patients (e.g. NICE, 2015c). Information includes, for instance, advice on ‘healthy eating’ (Public Health England, 2017a; NHS Choices, 2018c) and physical activity (NHS Choices, 2018d). A set of key messages are conveyed by such sources, for example: eating five portions of fruit or vegetables per day (NHS Choices, 2017); reducing intake of fat, sugar, and salt; monitoring and restricting energy (calorie) intake; ‘moving more’ (doing at least 150 minutes of physical activity per week); stopping smoking; and limiting alcohol consumption to a maximum of 14 units per week (NHS Choices, 2018a). Campaigns such as ‘Change 4 Life’ (2018) and ‘One You’ (2018) target individuals directly through posters and web based interactive tools and information in order to “encourage positive behaviour change and take-up of the NHS Health Check” (Public Health England, 2015d). Similarly, the new ‘All Our Health’ programme (which is supposed to “maximise the impact healthcare professionals in England can have on improving health outcomes and reducing health inequalities”) (see 2.4) was gaining in prominence through this study. HCPs are expected to “Make Every Contact Count” (MECC)— i.e. to use “every available opportunity” (the “day to day interactions that organisations and individuals have with other people”) to promote healthy lifestyle messages (Health Education England, 2017b), and to be alert to moments when patients may be more “teachable” (“situations where a particular event or set of circumstances results in an increased desire, willingness and capacity for individuals to alter their health behaviour in a positive way” (King, 2018)). MECC has been understood to be a ‘first level’ behavioural intervention to be delivered

to anyone as the opportunity arises (Bishop, 2015), which may be followed by 'level 2' brief advice, and subsequently more intensive support. These opportunistic approaches are promoted by the Royal College of Nursing (2018) and recommended as part of the NHS Health Check programme (see 4.3 below).

Following identification of a specific lifestyle related CVD risk factor, guidelines recommend that HCPs deliver 'brief interventions', most commonly in the form of 'brief advice' or 'very brief advice'. As the name suggests, these textual formulations are designed to fit within routine clinical practice (i.e. existing contacts with patients), 'brief advice' being "given typically in less than 10 minutes" and 'very brief advice' being "given as the opportunity arises in less than 30 seconds" (NICE, 2018a). The expected content of advice, and the approach to delivery, draw from individually-orientated theories of behavioural psychology and behavioural economics (Holman et al., 2017). In one guideline, 'brief advice' is defined as "verbal advice, discussion, negotiation or encouragement, with or without written or other support or follow-up" and "[varying] from basic advice to a more extended, individually focused discussion" (NICE, 2013). It may be included within routine general practice consultations, but may also be delivered by another commissioned provider. In the latter case, HCPs may complete a formal referral, or signpost to another service, depending on local commissioning and administrative arrangements. 'Very brief advice' has increasingly been considered to be particularly useful due to the time pressures of clinical practice, and to be suitable for delivery by all frontline HCPs as part of routine consultations (see, for example, Fuller, 2015 which outlines how nurses should fit brief interventions into their "everyday work").

The long-term impact of lifestyle interventions such as brief advice can be difficult to evidence through randomised controlled trials. However guidelines incorporate such activities based on the evidence available. Although brief advice (including 'very brief' advice) has been found to be less *effective* than some more time-consuming interventions, it is also understood to be more *cost-effective* (Aveyard et al., 2012) and to make the most of opportunities which present in the course of everyday practice (Fuller, 2015). In the absence of major and sustained improvements to people's health from lifestyle interventions, these brief interventions have become an increasingly prominent approach within healthcare

services. The increasing importance of this time-constrained advice is indicated by its incorporation as a performance measure within the Quality and Outcomes Framework (QOF) (see 2.7); general practices are, for instance, now paid for keeping a register of people who smoke, and (crucially) for achieving a target percentage of patients who “have a record of an offer of support and treatment within the preceding 24 months” (NHS Employers, 2016a) — see Appendix 4.

As highlighted above, brief lifestyle interventions and advice draw on behavioural psychology, and in particular techniques such as ‘motivational interviewing’. Although NICE has considered that there is insufficient evidence to support the technique’s formal recommendation (NICE, 2014a), it is increasingly being recognised within authoritative texts (see, for example, Public Health England, 2016c which links to a motivational interviewing learning module), and training courses widely commissioned (Matthews-King, 2014) — which were referenced by study informants. As Fuller (2015) explains, “the efficacy of brief interventions – whether or not they produce immediate change – depends on listening to the person’s point of view, often using competencies from motivational interviewing”. Motivational interviewing is understood to facilitate conversations about lifestyle and is seen as dampening the potential antagonism which may be generated when HCPs initiate discussion with patients about lifestyle related issues (Rollnick et al., 2008). The underlying assumption of this technique is that individuals’ failure to conform to understandings of a ‘healthy lifestyle’ are due to a lack of motivation, i.e. that motivation is the major factor. The role of HCPs within this knowledge framework is to support patients to discover their own latent motivation (Rollnick et al., 2008).

As well as brief interventions in routine clinical practice, guidelines also recommend that additional services to support lifestyle change are offered. Types of recommended services include: weight management programmes (NICE, 2014g); structured education programmes for newly diagnosed individuals with T2DM (NICE, 2015d); alcohol services (NICE, 2011a); and smoking cessation services (NICE, 2018a). The roll-out of a new national NHS Diabetes Prevention Programme (NHS England, 2016b) started during this study following commitments in the Five Year Forward View to addressing the burden of T2DM (NHS England, 2014a; NHS DPP Programme Support Team, 2016). The

increasing focus on interventions which support people with ‘behavioural’ and ‘metabolic’ risk factors (including diabetes⁵⁶, hyperglycaemia, hypertension, hypercholesterolaemia) reflects their importance in Global Burden of Disease analyses of CVD risk (Newton et al., 2015), as discussed in Chapter 2 (see 2.2 and 2.5).

4.2 Medical treatment of risk conditions

The overarching approach to general population educational advice and support for lifestyle change are the basic building blocks upon which the healthcare-orientated model of CVD prevention is developed. On identification of a biomedical risk condition (e.g. diabetes, hypertension), lifestyle change is understood to be even more important, and guidelines which relate to these metabolic risk conditions emphasise that lifestyle change may be able to bring biomarkers back into ‘normal’ range (e.g. NICE, 2015d).⁵⁷ However, these guidelines also recognise that patients may have trouble realising, or persisting with, major lifestyle changes (see also McNaughton and Shucksmith, 2015), and that meeting target biomarker thresholds may not be possible with lifestyle change alone. They therefore recommend that, if success is not achieved within only a few months, pharmacological treatment should be introduced.

There are multiple different medical treatments for CVD risk conditions and a variety of guidelines which relate to them, including at least eight different groups of medications for T2DM (Diabetes UK, 2018) and five for hypertension (NHS Choices, 2018b). Management of risk conditions involves regular monitoring of biomarkers in standardised appointments known as ‘reviews’ which are designed to facilitate good management of chronic conditions (as incentivised through the QOF)) and conscientiously ensuring that biomarkers are maintained at target levels in line with the relevant clinical guideline — and/or conducting other monitoring activities (Appendix 4). Although guidelines recognise the need for HCPs to sometimes set individualised targets, the recommendations include

⁵⁶ T2DM is categorised as a *disease* in GBD indices so does not appear in GBD lists of *risk factors*.

⁵⁷ Note that values considered to be ‘normal’ for risk factors have been subject to change over time, and have been controversial (see, for example, Glasziou et al., 2013).

standardised targets such as blood pressure of <140/90mmHg (NICE, 2011b) or glucose levels of <53mmol/mol (NICE, 2015d) which are reinforced through the QOF incentive programme; both research and policy focus on ensuring that these targets are met in order to reduce CVD risk. Within the dominant risk management discourse, patients are represented as needing to comply with medication regimes, and HCPs are represented as needing to overcome “inertia” and vigilantly monitor their patients (e.g. Schwartz and McManus, 2015). An extensive literature studies lifestyle and medication ‘compliance’ / ‘adherence’ for CVD prevention (see, for example, McNaughton and Shucksmith, 2015 who studied “adherence” to medication and advice in patients with high CVD risk).⁵⁸

4.3 The NHS Health Check programme

As introduced in Chapter 2, the NHS Health Check programme was developed as a population-level intervention designed to identify new ‘cases’ of risk.⁵⁹ The programme is a standardised effort to bridge the apparent gap between the broad emphasis on lifestyle habits that are expected to reduce CVD risk, and concurrent efforts to initiate targeted intervention (lifestyle and/or medical therapeutic guidelines) for people who are discovered to have demonstrable CVD risk factors. It was rolled out in 2009, with funding allocated to Primary Care Trusts to support the programme (Vascular Checks Programme, 2008). Later, it became a key constituent of the Health Improvement domain of the Public Health Outcomes Framework (PHOF) (Department of Health, 2011b, 2013b) with provision of the check’s main element (risk assessment) being made a statutory duty as part of the 2013 central government reorganisation of the NHS (Health and Social Care

⁵⁸ Other literature has approached ‘adherence’ from a more patient-orientated perspective, focusing instead on patients’ preferences and attitudes in relation to preventive activities. This work has highlighted tensions between patients’ preferences and, for instance, authoritative presentations that patients “need” to take preventive medications (e.g. Eborall and Will, 2011) (Eborall and Will found that when HCPs’ presented medications as a “necessity”, patients were more comfortable with taking them).

⁵⁹ Armstrong (1995) has documented the rise of what he calls “surveillance medicine” or “screening” for risk. He argues that, in new forms of surveillance medicine, the traditional model of medicine is inverted; instead of patients seeking doctors for alleviation of symptoms, doctors seek out patients in order to discover hidden (asymptomatic) disease or *potential* for disease (Armstrong, 2012). This type of medicine, he argues, is also distinct from traditional forms of medicine by virtue of its aetiological uncertainty; the multifactorial nature of CVD risk, for instance, means that prediction of CVD is unavoidably speculative and everyone in the population is potentially ‘at risk’ (ibid.).

Act 2012; Local Government Association and Public Health England, 2013). The strategic importance of the checks has been reinforced in numerous policy and guidance documents (e.g. Public Health England, 2016e) and is seen by policymakers to be the single most important intervention responding to the call to ‘get serious about prevention’ by providing a population-level, coordinated approach to identifying and managing risk (NHS England, 2014a). The Health Check has been developed in a standardised format in which an HCP collects information about an individual, conducts a series of tests, and then calculates a risk score (see below). The individual is then offered advice and/or referral to address identified risk. Although allowing for minor variations, delivery of the programme should conform to a set of ‘programme standards’ across delivery locations (Public Health England, 2014c).

The Health Check programme as a whole has been criticised by some GPs for not being ‘evidence based’ (McCartney, 2013; Capewell, 2008; Price, 2015), and for having avoided the scrutiny that would have been required if it had been formally classified and funded as a population-based screening programme (Capewell et al., 2015). However, national CVD leaders have argued in response that, although uncertainties remain about the *delivery method* (the Health Check as an intervention), each of the *constituent interventions* packaged by the programme is nonetheless ‘evidence based’ (The Primary Care CVD Leadership Forum, 2015). They argue that the urgency of prevention requires that they act quickly and monitor the programme as it develops (Waterall et al., 2015; Kearney and Waterall, 2016). I discuss some of the debates about the evidence for constituent interventions in 4.4 below. In any case, most health centres have opted to provide Health Checks in addition to their work under the GP contract.

4.3.1 Risk scoring

Central to the Health Check programme is risk scoring technology, used to calculate an individual’s personal level of risk for CVD (Public Health England, 2016e) (see also Will, 2005; Rothstein, 2003 for histories of risk scoring). Risk scoring technology originated with the ‘Framingham Risk Score’⁶⁰, but since then

⁶⁰ Developed from the Framingham Heart Study (2.1).

other calculators have been developed which use “risk function equations based on multivariate risk models derived from large population databases” (Bitton and Gaziano, 2010). At first these calculators were in the form of look-up tables, but more recently they have been made more accessible in clinical practice through the use of algorithms embedded in digital technology. Risk scoring is now established as the basis for population-level CVD prevention activity worldwide (Bitton and Gaziano, 2010; Collins et al., 2017; World Health Organisation, 2007; Stone et al., 2014; Department of Health, 2013a; NICE, 2014b).

In England, QRISK2 risk scoring technology is used (Hippisley-Cox et al., 2007; Collins and Altman, 2012). A patient’s demographic and biometric data are entered into the risk calculator (embedded into the Health Check electronic template), to calculate the risk score. Their ‘overall’ risk (sometimes also called ‘total’, or ‘absolute’, risk) is quantified by aggregating the impact of their individual risk factors to produce their *personalised* risk of experiencing a cardiovascular ‘event’ (e.g. heart attack, stroke) over a specified time-period — usually ten years, as is the case with QRISK2 (I take up a more detailed analysis of the risk scoring process in Chapter 7). Described as a new ‘paradigm’ in the management of CVD risk (e.g. Karmali et al. (2017)), the calculation of risk score within this paradigm is institutionally significant, since it enables policymakers to stratify prevention efforts at a population level based on ‘big’ epidemiological data — “[focusing] resources on those at greatest risk, and hence with most to gain” (NICE, 2014f; Karmali et al., 2017). This calculative process is thought to be a more objective way of understanding the needs of *both* individuals *and* local populations.

In England, the main guideline which coordinates HCPs’ work to manage an individual’s ‘overall risk’ (including risk scoring technology) is entitled ‘Cardiovascular disease: risk assessment and reduction, including lipid modification’ (NICE, 2014b), hereafter connoted by its NICE reference number, CG181. Not only does the risk score quantify risk, but it also forms the (textual) basis for offering lipid-lowering treatments, primarily with statin medications (Joint British Societies, 2005). This direct textual link (between the risk and statins) is exemplified in Figure 18, and is based on scientific reasoning about the role and clinical effectiveness of statin medications. The recommendation to prescribe lipid modification therapy, regardless of a patient’s blood lipid profile, is complex

and controversial (see 4.4 below). It is based on several influential studies of statin efficacy which have shown that lipid-lowering (whatever the baseline lipid level) reduces risk (see, for example, Ridker, 2009; Harvard Health Publications, 2012).⁶¹ This evidence, combined with risk scoring technology, has enabled policymakers to develop and circulate guidelines which include, for example, authoritative textual ‘moments’ in which a decision should be made (as shown in Figure 18).

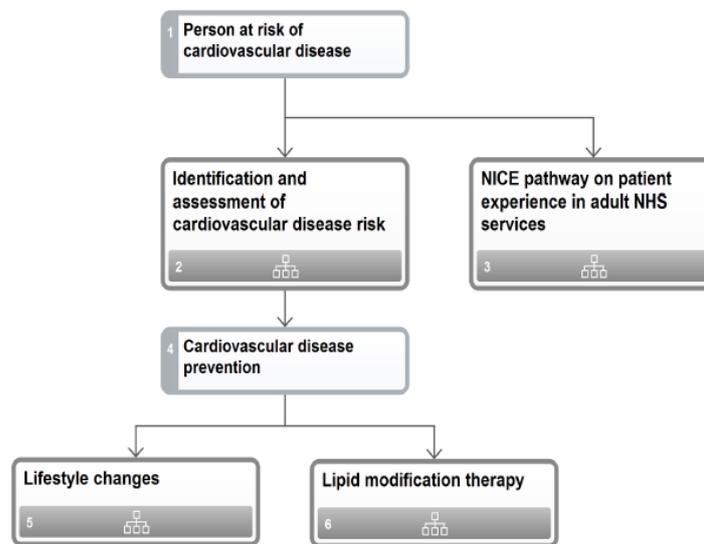


Figure 18: Cardiovascular Disease Prevention Overview (from NICE, 2014b)

The textual construction of this ‘moment’ has been developed according to contemporary calculations of cost-effectiveness. For instance, in the 2014 update to CG181 (NICE, 2014f), a change was made to the threshold overall/absolute risk score at which patients would be considered as ‘high risk’ (decreased from 20% ten-year risk to 10% ten-year risk). This was largely due to the decreased price of statins after coming ‘off-patent’, and therefore calculations of increased cost effectiveness (NICE, 2014f, pp.192–194).⁶²

⁶¹ This approach was largely determined by the structure of the original statin trials which used fixed doses of statins rather than ‘treat to target’ therapy (Ross et al., 2016).

⁶² Such economic influences have also been a consideration in determining threshold levels for intervention in relation to single risk factors (e.g. threshold blood pressure for treatment with antihypertensives).

CG181 links HCPs into a new scientific formulation of risk and the benefits of statin therapy. One aspect of this ‘newness’ is that there is no requirement for an abnormal biomarker to be identified in an individual patient, prior to a clinical decision about statins. Accordingly, preventive medication has been extended not only to an asymptomatic population with an abnormal biomarker, but also (in cases where an individual’s data generates a high risk score) to a wider population in whom there is no evidence of disease or even any ‘abnormality’ in standard blood test results (see 4.4.5 below and also Chapter 6) — particularly older patients whose 10-year risk will inevitably be high regardless of abnormal biomarkers.

4.3.2 Improving uptake and the imperative to attend

The importance of ensuring a good ‘uptake’ of the Health Check is threaded throughout CVD prevention guidelines and related research literature. Uptake is also an indicator in the Public Health Outcomes Framework (Department of Health, 2013b) on the basis that improving uptake is modelled to improve population health through assumptions about new cases diagnosed and treated.⁶³ (An assumption that 75% of the eligible population would attend the check was built into modelling assumptions ((Department of Health, 2008a)). As policymakers promote the Health Check, they extend risk management discourse into the public sphere. The following extract is part of material provided to patients that outlines the Health Check’s key features and seeks to promote uptake.

“The Health Check is a sophisticated check of your heart health. Aimed at adults in England aged 40 to 74, it checks your vascular or circulatory health and works out your risk of developing some of the most disabling – but preventable – illnesses. Think of your Health Check as being your “midlife MOT”. It checks that some of your body’s most important systems are all running smoothly. Among other things, your blood pressure, cholesterol, and BMI will all be checked and your results given to you. Crucially, your Health Check can detect potential problems before they do real damage.

⁶³ A 10% improvement in the Health Check indicator is estimated to result in a 0.002 year improvement in average life expectancy (Department of Health 2011).

Everyone is at risk of developing heart disease, stroke, type 2 diabetes, kidney disease and some forms of dementia. The good news is that these conditions can often be prevented. Your Health Check will assess your risk of developing these health problems and give you personalised advice on how to reduce it. It's free of charge, including any follow-up tests or appointments.” (NHS Choices, 2016b)

This presentation of the Health Check, developed for patients, introduces the concept of CVD risk and the need to have this assessed by an HCP. Vigilant body ‘maintenance’ is emphasised through the use of an MOT analogy, which likens the patient’s body to a car, which is put through regular mandatory tests to ensure roadworthiness (GOV.UK, 2017). This idea was cited by patients participating in research on the Health Check (e.g. Brophy, 2015), and also by patients interviewed for this study. The case for attendance is made by emphasising the likelihood of future disease and the personal opportunity to avert health problems by attending the check. The patient’s work here is represented as simple — attend your Health Check, discover your risk of disease, and take advice on how to reduce it.

Key analyses of the Health Check have been commissioned by: Public Health England (e.g. Usher-Smith et al., 2017)⁶⁴; the Department of Health Policy Research Programme (e.g. Artac et al., 2013; Chang et al., 2015, 2016; Robson et al., 2015, 2016); and by commissioners (e.g. Brophy, 2015; Cochrane et al., 2013; Perry et al., 2016). Another was produced by Public Health England’s Expert Scientific and Clinical Advisory Panel (2017).⁶⁵ This research has focused on “attendance, delivery and health outcomes” (Usher-Smith et al., 2017), in response to the stated concerns of national policymakers. *Uptake* of the checks

⁶⁴ This is a “rapid evidence synthesis” produced by researchers at the Primary Care Unit at the University of Cambridge. It is the most contemporary, and therefore influential, review currently in circulation.

⁶⁵ These research publications are generally labelled as academically ‘independent’ from influences by funders, although in some cases potential conflicts of interest relating to, for example, involvement in policymaking, or an author’s income from e.g. pharmaceutical companies (see, for example, Chang et al., 2016) are noted. Some other research (which apparently has no funding, or other, connection to the national Health Check programme) has also been published — although these studies are not at the scale or influence of the commissioned publications mentioned here.

has been an ongoing focus because it has consistently fallen below the modelled 75% uptake (as above), and has led to further research on reasons for non-attendance (e.g. Usher-Smith et al., 2017; Brophy, 2015). To date, only approximately half the eligible population in England has attended, which is disappointing for policymakers who are convinced of the Health Check's value (and cost-effectiveness) in improving population health outcomes (Kearney, 2017).⁶⁶

Because the Health Check has been officially understood as an intervention which will particularly benefit individuals with unhealthy lifestyles (shown to be more prevalent in deprived communities), and because its modelled cost-effectiveness depends in part on gaining uptake among such groups, policymakers have also been keen to demonstrate that those attending are from these communities (Kearney and Waterall, 2016). Such analyses (e.g. Expert Scientific and Clinical Advisory Panel, 2017) have responded to the criticisms of some HCPs who have claimed, firstly, that the Health Check perpetuates the 'inverse care law'⁶⁷ (i.e. that it is the "worried well" who attend – people with relatively healthy lifestyles, who turn out to be 'low risk' upon attending the check (Riley et al., 2015; McCartney, 2013)) and secondly, that its focus on individual risk pulls HCPs' attention away from those who need it most (Glasziou et al., 2013).

4.3.3 Discussions about how HCPs and patients understand risk

Research relating to the Health Check (as above) has also tended to orientate around its central logic — that patients should attend in order to discover their individual risk, and take action in light of it. The most recent research synthesis, conducted by Usher-Smith et al. (2017), picked up on ways in which delivery of the Health Check has diverged from the programme's standards, particularly in relation to HCPs' 'communication' of risk (and patients' understanding). For instance, Usher-Smith et al. find that HCPs do not always tell patients their risk score. However, the findings of qualitative and quantitative studies (as

⁶⁶ Matt Kearney is National Clinical Director for Cardiovascular Disease Prevention.

⁶⁷ The inverse care law maintains that "the availability of good medical care tends to vary inversely with the need for it in the population served" (Tudor-Hart, 1971).

synthesised by Usher-Smith et al.) also indicate that, even when patients *are* given this information, they may find it confusing or irrelevant. This leads Usher-Smith et al. to direct readers to the growing research evidence base investigating how risk may be best communicated to patients (e.g. Zipkin et al., 2014).

Research relating to how notions of risk are understood by both HCPs and patients (e.g. Waldron et al., 2011; Zipkin et al., 2014; Spiegelhalter, 2017) has emphasised the difficulties of communicating probabilistic knowledge of risk in a way which is meaningful to patients — i.e. both accurate and easy to understand (see, for example, Gigerenzer et al., 2007 who demonstrated widespread statistical illiteracy among doctors and patients). Research on tools, such as patient decision-aids, has proliferated to support HCPs with this task, many of which have been produced by researchers promoting ‘shared decision-making’ (e.g. Stacey et al., 2017). Although these are not yet routinely produced by NICE, a patient decision-aid relating to statin medications was produced to accompany CG181 (NICE, 2014i) in response to the controversy that has surrounded the guideline. This uses visual representations of risk alongside suggested wording to be used by HCPs. In authoritative policy texts it is assumed that, when risk is communicated ‘well’ to patients, they will usually follow the recommended course of action. This sits alongside the increased application of ‘shared decision-making’ *principles*, which have been adopted and promoted by guideline developers (recognising patients’ right to act differently to recommendations, according to their “values and preferences” (NICE, 2012b)) — see 4.5 below. (I also provide a more detailed analysis of ‘risk communication’ in the practices of frontline HCPs in 7.5).

4.4 Debates about the evidence

Many of the interventions already outlined in this chapter (known as CVD prevention) have been the subject of considerable debate in the clinical academic community. In this section, I very briefly outline some major challenges (by academics and activist HCPs) to the dominant approaches to managing CVD risk.

4.4.1 The statin controversy

As introduced in Chapter 3, many debates about the evidence for interventions have focused on preventive medications, which, it has been speculated, could do more 'harm' than 'good' in the trade-off between long-term benefits and current side-effects. Here, I briefly outline the debate about statin medications that is particularly prominent in the discourse — a debate that relates directly to the measurement and management of CVD risk through risk scoring.

Critique of the universal recommendation to offer statins to 'low risk' patients without evidence of CVD has focused on the discrepancy between reports of side-effects (e.g. muscle myopathy) arising from frontline clinical practice and observational studies, and authoritative representations of adverse effects reported in the major clinical trials of statins (Cholesterol Treatment Trialists' (CTT) Collaboration, 2010; Abramson et al., 2013). Abramson et al. have highlighted apparent flaws in the CTT's meta-analysis of clinical trials of statins including potential bias in the assessment of 'outcomes' and a lack of transparency over side-effects.⁶⁸ In addition, they highlighted the potential for trial data, and its interpretation, to be indirectly influenced by pharmaceutical funders, who have invested huge sums in conducting trials and promoting statins but have not allowed research data to be released for wider scrutiny.

Abramson et al.'s criticisms led to an acrimonious dispute which involved not only researchers, but also the editors of the BMJ and the Lancet (coined the 'statin wars' (Husten, 2016)), and revolved around controversial publications in the BMJ. The formal dispute culminated in a review by a BMJ panel (BMJ Editor, 2014) which recognised the uncertainty of the evidence about both clinical effectiveness of statins and their adverse effects, and the potential for different interpretations. The editorial panel called for the trial data to be made available to those outside the University of Oxford's CTT Collaboration. Critics such as Abramson (2015) have continued to argue that "practically all that we think we know about the efficacy and safety of statins has been brought to us by commercial interests that

⁶⁸ The CTT meta-analysis did not report serious adverse effects and the scale of other side-effects reported was inconsistent with major previously-reported studies. As the CTT did not make the trial data available to other researchers, many questions remain about the data reported in relation to adverse effects.

hold the actual data as proprietary secrets”, and that particular dietary interventions (see below) are more effective and important than statin therapy (Hobbs et al., 2016). However, as the US-equivalent guideline to CG181 makes clear, “because the overwhelming body of evidence came from statin RCTs, the Expert Panel⁶⁹ appropriately focused on these statin RCTs to develop evidence-based guidelines for the reduction of [atherosclerotic CVD risk]” (Stone et al., 2014), and the evidence supporting CG181’s recommendations to offer statins has mostly been assessed as having minimal ‘risk of bias’ (NICE, 2014f).

Although the debate about statins has focused on the reporting of *side-effects* in clinical trials, there is also considerable controversy over the *aetiological mechanisms* involved in atherosclerotic CVD (in particular the role of blood cholesterol), and correspondingly in the mechanisms involved in statin therapy (e.g. Stancu and Sima, 2001; DuBroff and de Lorgeril, 2015). Several high-profile clinical academics have challenged the predominant hypothesis of statin effectiveness (The International Network of Cholesterol Skeptics, 2016; Demasi et al., 2017).⁷⁰ Described critically as the ‘cholesterol (or ‘lipid’) hypothesis’, the theory rests on an understanding “that cholesterol, particularly LDL-C [commonly known as ‘bad cholesterol’⁷¹], is inherently atherogenic” (Ravnskov et al., 2016). Related to this critique was another of the ‘diet-heart-hypothesis’ which directly links cholesterol intake (especially saturated fats) with blood cholesterol levels and cardiovascular disease (DuBroff and de Lorgeril, 2015). The particulars of both hypotheses continue to be vigorously contested, and multiple sources of information are available to patients regarding both medications and diet (see for example the Diabetes UK online forum <https://forum.diabetes.org.uk/boards/>).

4.4.2 Medications or lifestyle change?

As a result of uncertainties over the benefits of statins, some CVD researchers and clinicians question the emphasis on lipid modification with statin medications following the calculation of a ‘high risk’ score. Although recommendations to

⁶⁹ Responsible for the guideline’s development.

⁷⁰ Many of whom have been, formally or informally associated with an international network of “cholesterol skeptics” (see, for example, THINCS, 2018).

⁷¹ See e.g. Heart UK (2016).

promote lifestyle change are threaded throughout CG181 and other guidelines relating to CVD prevention (see Figure 18), they highlight that ultimately statin medications should become the focus of recommendations when a patient is discovered to be high risk (NICE, 2014b). For instance, the NICE decision-aid accompanying CG181 (the main guideline for CVD risk management) only provides information to support patients in making a choice *about statins* in response to a high risk score. Some people within the clinical academic community have been concerned about this emphasis on medications, and the consequent *de-emphasis* on lifestyle change. This has led to calls for the promotion of a particular brand of lifestyle change, sometimes known as “lifestyle medicine” (involving, for instance, a Mediterranean diet, a good exercise routine and stress reduction) (Malhotra, 2016), and a readjustment of policy to reflect the value of lifestyle change (e.g. Carlos et al., 2014).

Prominent campaigners against ‘medicalisation’ have produced alternative risk calculators (e.g. Option Grid Collaborative, 2014; McCormack, 2017), which provide information about the relative benefits of particular lifestyle changes *together with the benefits of statins*, and therefore enable comparison of medication and/or lifestyle change. These aim to provide patients with better, more up-to-date information on the *scale of benefit* offered by particular pharmaceutical interventions (presented for instance as Number Needed to Treat (NNT) or Number Needed to Harm (NNH)) (a thread taken up in Chapters 7 and 8). Such calculators preferentially select studies which demonstrate ‘hard’ mortality/morbidity outcomes rather than those which extrapolated from surrogate outcomes (e.g. cholesterol reduction).⁷²

4.4.3 Dietary guidelines

Alongside, and directly related to, the debate about statins runs another high-profile debate about the evidence behind dietary guidelines as represented by, for instance, the Eatwell Guide (see Figure 19).⁷³

⁷² It is beyond the scope of this study to interrogate these tools in detail. The information presented here is primarily from activist informants.

⁷³ The so-called “statin wars” (Husten, 2016) started with the publication of two articles in the BMJ (BMJ Editor, 2014) — one challenging the evidence for statins (Abramson et al., 2013), and the other challenging understandings about saturated fat and cholesterol (Malhotra, 2013a).



Figure 19: The Eatwell Guide (from Public Health England, 2016f)

A new international movement has emerged to challenge the longstanding “demonisation” of dietary fats (Diamond, 2015) and expose the origins and history of dietary guidelines as influenced by politics and the food industry (see, for example, The International Network of Cholesterol Skeptics, 2016) — which have resulted in one third of the Eatwell Plate being made up of carbohydrates (including processed carbohydrates). Critics of the recommendation to strictly limit dietary fats (see, for example, The Noakes Foundation, 2018; Lustig, 2014), have claimed that its basis is fundamentally flawed. They argue that its premise, that blood cholesterol is a major risk factor for CVD, and that lowering it can be achieved through reducing fats *in the diet*, is based on evidence skewed towards food industry ambitions (e.g. Malhotra, 2013a; The International Network of Cholesterol Skeptics, 2016). Instead, critics of the accepted wisdom (which emphasises reduction in dietary fats) propose that total blood cholesterol (which includes ‘good’ LDL particles as well as ‘bad’ HDL particles) is not, as previously accepted, a major risk factor for CVD. Instead, *only HDL* particles are harmful, and reducing dietary fat is not effective at reducing these particles. Guidelines which promote a low-fat diet (that relies more on carbohydrates) may, they argue,

be implicated in population increases in metabolic abnormalities leading to obesity and T2DM (e.g. Public Health Collaboration and National Obesity Forum, 2016; Noakes, 2015; DiNicolantonio et al., 2016; The International Network of Cholesterol Sceptics, 2016). Alternative pathophysiological mechanisms which emphasise the role of carbohydrates (especially quickly-metabolised sugars) in metabolic disorder (e.g. insulin resistance) have been proposed as central to the development of CVD (Demasi et al., 2017) — although answering the question of ‘what causes heart disease?’ remains an ongoing quest (Kendrick, 2017).

Campaigners have consistently based their controversial ideas on ‘the science’ (and its interpretation) and, despite some considerable scepticism (e.g. Scotland, 2016; Snowden, 2017), the movement has gained considerable momentum in the UK as well as elsewhere — perhaps in part due to stories of frontline success arising from GPs supporting patients with alternative dietary approaches to weight loss (Unwin and Tobin, 2015). The alternative guidelines developed by the Public Health Collaboration and National Obesity Forum (2016)⁷⁴ promote what they describe as ‘real food’ (which reflects “how foods come in their natural form”) and caution against high density carbohydrates (especially sugars) (ibid.). Such diets, which claim to use a different scientific ‘evidence base’ to those of the Eatwell dietary guidelines, include versions of the ‘Mediterranean Diet’ (e.g. Malhotra and O’Neill, 2017) and other ‘Low Carb High Fat’ diets (Diet Doctor, 2018; Real Meal Revolution, 2018).

4.4.4 Multimorbidity and polypharmacy

Another contention relates to how CVD prevention guidelines impact on the clinical management of patients with ‘multimorbidity’ — i.e. patients (often older)

⁷⁴ The Public Health Collaboration is a “charity dedicated to informing and implementing healthy decisions for better public health” by publishing “evidence-based reports on the most pressing public health issues alongside coordinated campaigns and implementing initiatives for improving public health” (Public Health Collaboration, 2018). The National Obesity Forum is “raising awareness of obesity in the UK and promoting the ways in which it can be addressed” (National Obesity Forum, 2018a). Prominent campaigners are involved in both, dedicating their time “pro-bono” to the cause.

The National Obesity Forum recognises sponsorship from a number of partners including those in the pharmaceutical, diet, and food industries (National Obesity Forum, 2018b). Campaigners also raise funds from speaking and book sales, although I found no evidence that this was the originating motivation behind their work.

who have been diagnosed with several different conditions. Treadwell (2015), for example, highlights that these patients make up 80% of consultations in general practice but are usually not represented in research trials (individuals are usually excluded from trials if they have comorbidities). Using a case-study of an 82-year-old woman with several common comorbidities, Treadwell demonstrates that she would, according to clinical guidelines, be recommended at least 10 different medications, some of which are preventive. Like Dan (see Chapter 1), she wants to avoid heart attack and stroke, but takes a philosophical view of her own mortality. Treadwell calls for more “clinically meaningful evidence resources” which would make the evidence lying behind guideline recommendations more accessible to the practising clinician who is trying to tailor decisions about care (especially preventive medications) to an individual patient. This, he claims, would allow the GP to support more ‘patient-centred’ decisions about care and avoid the harms associated with polypharmacy and over-zealous adherence to single-condition guidelines (see Scott et al., 2014 on the need to deprescribe in older patients; and Kearney et al., 2017 for a recognition, even among strong “prevention” proponents, of the need for individual tailoring).

4.4.5 Interventions focused on scientific surrogate outcomes to the exclusion of other elements of care

Finally, the use of ‘surrogate outcomes’ in research has been criticised; the issue has been important in the statins/cholesterol controversy. (‘Surrogate outcomes’ refers to research which demonstrates ‘success’ by, for example, demonstrating a reduction in a marker such as blood cholesterol or weight, rather than by demonstrating improved CVD morbidity and mortality endpoints.) First, critics claim that such researchers make assumptions about long-term compliance to particular medication or lifestyle regimes which may not be justified. Although a surrogate marker may be modified within the timescale of the research study, intervention may not be successful at reducing risk over the long term (Barry et al., 2015). Second, surrogate biomarkers may be “bystanders without an active role”, rather than being part of the causal pathway involved in the development of CVD — i.e. they are associated with better CVD outcomes but there is considerable uncertainty about whether the marker actually causes disease (Yudkin et al., 2011). Third, the focus on surrogate markers does not take account of the inevitability of human mortality — that patients all have a “finite functional

life” and that “age is a fundamental cause of disease” (Mangin et al., 2007). Reducing the blood pressure of an elderly person may, for instance, theoretically reduce CVD risk but their life may already be significantly limited by another condition. Reducing their blood pressure in this situation may change the *cause of death* but not actually *prolong life* to any significant degree (Mangin et al., 2007), incurring unnecessary healthcare resource use and potentially reducing the quality of their life in the process.

4.4.6 ‘Rationality’ and ‘humanity’

The prominent debates discussed in 4.4.1 to 4.4.5 focus on ‘evidence based’ interventions to reduce CVD risk. These debates are frequently bound up with more philosophical arguments about the balance of scientific “rationality” with “humanity” in the practice of medicine (e.g. Heath, 2016).⁷⁵ Key critics with clinical influence, such as Iona Heath (former president of the RCGP, and influential speaker on the harms of ‘too much medicine’), and other lobbyists within the Preventing Overdiagnosis (POD) movement (see 3.1), have argued for a return to clinical practice which focuses on alleviating patients’ suffering, ‘watchful waiting’, and on minimising the ‘disruption’ caused to patients by intervening (Lehman et al., 2015; May et al., 2009a).

Others too, both active within the POD movement (see Chapter 3) or similarly critiquing contemporary practices of medicine (e.g. Greenhalgh et al., 2015), have drawn attention to ‘humanistic’ aspects of clinical consultations, understood to be “empathy, compassion, the therapeutic alliance”, which they argue “are devalued and may be overlooked” (ibid.). They have drawn particularly on ideas about the negative effects of ‘disease labelling’ (as presented in *Figure 14*). The concept of disease labelling (which draws on theories that patients engage in mental or psychological work to manage risk, and derived from studies of “deviance” (Crinson, 2010)) suggests that a disease ‘label’ marks an individual as deviant, and impacts their “sense of self and identity” (Kelly, 2010). Such ideas

⁷⁵ Researchers have argued that the ‘rational choice model’ of decision-making promoted in policy is not consistent with the knowledge practices employed by patients (and in some cases, HCPs) (e.g. Polak, 2016). However, depictions of patients as basing decisions only on emotions rather than facts have also been criticised (e.g. Heyman, 2013). In either case, their focus is on the psychological components of making choices rather than on the institutional organisation of people’s decisions.

are linked to those relating to stigma (see footnote 55), and emphasise patients' work in "coping" with the label (ibid.). The POD movement (Chapter 3) has frequently raised the issue of "expanding definitions" of disease and the associated harms of extended disease labelling. These include both medical (scientific) concerns about unnecessary treatment (e.g. Moynihan et al., 2013) and also the more psychological effects of "fear" (see, for example, Rosenberg, 2009). Heath (e.g. 2013) in particular draws on such ideas about psychological harms, describing them as "ink of fear" in the "water of health" — and suggests that the underlying problem is a societal one relating to fear of death itself (Heath, 2014). These arguments have drawn from a rich and varied literature including that on 'medicalisation' (Busfield, 2017) which have permeated the debates outlined in this chapter.⁷⁶

4.5 The role of patients in prevention

How should decisions about preventive interventions be made? Who should be involved? What knowledge should be employed? As introduced in Chapter 3, a debate about 'evidence based medicine' (EBM) rumbled throughout the course of this study. Taking it up in detail here sits outside the analytical threads selected for explication in this thesis. It should be emphasised however that the EBM debate is closely linked to discussions about 'shared decision-making' (SDM) and appeals for more 'patient centred care'; proponents of 'real EBM' have advocated these principles (Greenhalgh et al., 2014; Heneghan et al., 2017) — see 3.1.2. Policymakers too have taken up the notion of SDM. They have been spurred on following a UK Supreme Court ruling which "pronounced that the process of gaining consent for any procedure which 'interferes with bodily integrity' should be informed by the principles and practice of shared decision-making" (Collins, 2016). However, they take up the concept of SDM from a slightly different perspective to some other proponents; the incorporation of an SDM workstream

⁷⁶ I do not expand on the sociological discussion of 'medicalisation' as this is significantly influenced by macro-theory (Conrad, 2013) and is not directly and empirically traceable to local practices of CVD prevention. The critique of medicalisation developed by the philosopher Ivan Illich (e.g. 1976) however is particularly influential within the Preventing Overdiagnosis movement. His concept of 'iatrogenesis' (harm precipitated by medical intervention) has been taken up to challenge forms of modern medicine which are alleged to do more harm than good (Donnelly, 2015), thereby undermining the historical foundations of medical practice (Sokol, 2013).

within the NHS RightCare programme⁷⁷ (which focuses on “increasing value” for patients and commissioners (BMJ Group, 2016c)) provides a clue to the institutional logic involved:

“The aim of the Right Care Shared Decision-Making Programme is to embed Shared Decision-Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make “no decision about me, without me”⁷⁸ a reality. The Shared Decision-Making programme is part of the Quality Improvement Productivity and Prevention (QIPP) Right Care programme. In 2012, the programme entered an exciting new phase and, through three workstreams, is aiming to embed the practice of shared decision-making among patients and those who support them, and among health professionals and their educators.” (BMJ Group, 2016b)

The cost-saving logic of SDM within the QIPP programme can be achieved in one of two ways. If some patients decide to decline *high cost per QALY* interventions, the logic goes that this will save or defer immediate healthcare costs.⁷⁹ However, as I have indicated in this chapter, and in Chapter 2, preventive interventions are calculated to achieve low cost per QALY (very cost-effective), and some are calculated to additionally produce longer-term *cost savings* for the healthcare system. Within the policymaking practices of risk management which I have shown in this chapter, policymakers emphasise the need for patients to actively ‘engage’ in preventive interventions, and have increasingly focused on measuring and/or remedying deficits in their individual ‘engagement’, ‘motivation’, ‘activation’, or ‘capability’ (for an overview/discussion of these ideas, see Hibbard and Greene 2013; Entwistle and Watt 2013; Entwistle and Cribb 2013). The

⁷⁷ NHS RightCare was rolled out in 2015 as a collaboration between various prominent UK health agencies following dissolution of a previous cost-saving programme (QIPP)⁷⁷ and was implemented to support the NHS Five Year Forward View (Cripps, 2015; NHS RightCare, 2015)

⁷⁸ This phrase refers to the government paper ‘Liberating the NHS: No Decision About Me Without Me’ (Department of Health, 2012).

⁷⁹ Although all healthcare interventions are provided on the basis of cost-effectiveness, the cost per QALY is a prominent organiser of policymaking work. For some interventions, the high cost per QALY means that commissioners will save costs if a patient declines treatment (see Elwyn et al., 2010) — especially in older patients who will not accrue many years of costs as a result of any disability from not undergoing the treatment.

evidence presented here, and my data presented in subsequent chapters, suggest that SDM is increasingly understood as an approach which will encourage patients to *comply* with medication regimes.

However, as I have highlighted previously, although there is broad consensus about the basic aspirations of SDM (e.g. encouraging patients to be involved in decisions), there is significant discrepancy in how the idea is activated. For instance, whereas policymakers may understand SDM as a model to facilitate decisions which are more in line with guideline recommendations, other groups, such as those challenging ‘overdiagnosis’ and ‘overtreatment’, have appealed for SDM on the basis that it may facilitate decisions which do *not* conform to guideline recommendations but are more in line with patients’ preferences (Misselbrook and Armstrong, 2001) (see 3.1). Discrepancies in the *meanings* associated with particular terms and ideas (as used by people in different institutional locations) are a persistent feature in this study, as discussed theoretically in 3.2, and showed in practice in the following chapters.

4.6 Summary

In this chapter, I have shown that dominant knowledge of CVD prevention is based on a suite of interventions designed to identify and reduce a patient’s risk of developing CVD. As I highlighted in Chapter 2, these are calculated to be ‘evidence based’ (and cost-effective) based on research trials — and therefore to save people’s lives and enable them to avoid disease. Knowledge of risk management, which permeates clinical guidelines and policy/academic literature, indicates that patients *should* take up these interventions where they are classified (textually) as *needing* them — i.e. when are assessed as having a risk factor/condition. Within this frame, HCPs’ work is understood as being to promote these interventions and to ‘engage’ or ‘motivate’ patients, as they are “ultimately responsible” for their own health (see also 2.4). For many people, this participation starts with their attendance at a Health Check, understood to be an important entry point for vigilant attention to their CVD risk management; through it, they may be channelled to more targeted interventions, a process facilitated by the use of risk scoring technology, which provides a new way of classifying patients as needing to take action — textually indicating that they are eligible for lipid-lowering medications.

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However, I have shown that CVD prevention is riddled with uncertainties relating to: the scientific production of evidence for lipid-lowering and other preventive interventions; the calculations of how these will benefit population health (see 2.6); and the practices by which they should be applied in practice to individual lives. These uncertainties have generated considerable debate in the clinical and academic communities. I have highlighted that, although clinical guidelines provide recommendations, policymakers increasingly advocate that uncertainties are resolved in practice through ‘shared decision-making’. However, many debates circulate about how SDM should happen in practice and, as the approach has been increasingly adopted as a priority in policy literature, it has become increasingly associated with potential cost savings. Within the discursive practices of risk management and preventive interactions, SDM is positioned as a way of promoting adherence to cost-effective, and (sometimes) cost *saving* interventions (see 2.6).

A review of Dan’s story is pertinent at this point. As outlined in Chapter 1, standpoint is a fundamental ingredient of IE analysis — including during literature review. It orientates the researcher to “examine how knowledge works; whose knowledge counts” (Rankin, 2017b). The IE analyst recognises that the knowledge that ‘counts’ is often knowledge embedded in ruling relations, which may serve the interests that insert tensions into the work of those people in the standpoint location. In Dan’s story, his GP tried to persuade him that he ‘should’ be on medication to treat his atrial fibrillation — on the basis that medication would significantly reduce his risk of having a heart attack or stroke. Dan however brought a different knowledge to the encounter — of what he knew about the side-effects of the medication, and of the independent action he was taking to improve his overall health. These alternative knowledges conflicted with the knowledge of risk cited by his GP. Although issues such as side-effects of medication are undoubtedly an important part of his GP’s knowledge (that the GP too brought to the consultation), his expert medical view of Dan’s *need* to reduce his risk by taking particular medications overrode other considerations which Dan highlighted as important. This chapter has looked at the textual landscape shaping GPs’ and other HCPs’ knowledge — and ultimately Dan’s experiences. In the following chapters, I move back to the preventive interactions between

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HCPs and patients, and observe how knowledge of risk management is activated in frontline practice.

Chapter 5 Fitting lifestyle interventions into everyday life

This chapter is the first of four based on traditional ‘fieldwork’ (i.e. observations and interviews). It picks up from Chapter 1, where I presented Dan’s story and highlighted what I called ‘fitting work’ (1.1). This is the frequently troublesome work which he, and other patients, undertake to ‘fit’ authoritative forms of prevention into their everyday lives. For instance, Dan was offered preventive medication which might have significant side-effects. Fitting it into his life would involve not just taking tablets, but restricting his diet to avoid foods which will interact with the medication, managing the side-effects, and attending regular monitoring appointments — and much other secondary, ‘knock-on’ work. It also involves balancing different priorities (would it matter, for instance, that he could no longer eat kale?). In Dan’s case, he opted not to accept the medications, deciding that he would invest his efforts into a ‘good lifestyle’, and he clashed with his GP as a result. Dan is unusual in having managed to turn around his lifestyle, an experience of which he was proud, and which motivated him to participate in my study. As he volunteered to me later, he hoped that his story would show people what is possible when “you set your mind to it”.

In this chapter, for contrast, I start my analysis from my conversation with Naomi, a 44 year old woman who lives in one of the most deprived areas of the UK, and locally to Dan, and to Wildwood Health Centre. I select Naomi’s account for focused analysis, as her clustering of CVD risk factors makes her a prime candidate for prevention (as represented in policy — see Chapters 2 and 4, and as she clearly struggles with the forms of preventive work recommended. When the World Health Organisation highlight the growing problem of non-communicable diseases and their impact on the cost of healthcare provision (see, for example, Zimmet and Alberti, 2006), an individual like Naomi might come to mind. In particular, she exemplifies what is sometimes described as ‘Metabolic Syndrome’ (Eckel et al., 2005), a “constellation of closely related cardiovascular risk factors” including “visceral obesity, dyslipidaemia, hyperglycaemia, and hypertension” (Alberti et al., 2005). Metabolic Syndrome is also discursively linked with what is known as the “obesity”, “diabetes” or “diabesity” “epidemics” (see above citations), and is directly associated with unhealthy lifestyles.

The analysis presented here foregrounds disjunctures (3.7) between Naomi's 'version of reality' and that of the institutional processes with which her work intersects (Campbell and Gregor, 2002, p.48) — particularly standardised interventions which are supposed to support her with her 'lifestyle' and which textually transport knowledge about Naomi and her needs. Naomi does not *reject* this authoritative knowledge about her health, but it enters into her everyday life in troublesome ways. I particularly highlight Naomi's work to "have a conversation" with her GP about how to fit lifestyle advice into her individual context, and the ways in which the support proffered does not match with her understanding of her needs. Although, on first glance, it appears that Naomi is doing very little work (not playing her part in prevention), using IE's broad conception of work, and taking a closer look at how she interacts with the health centre, I uncover extensive work, which becomes a starting point for the analysis here. I supplement Naomi's account with that of other standpoint informants, and particularly draw attention to the work of HCPs and health trainers who work to 'motivate' patients. I show from their accounts that, although these interventions are designed to provide greater time and space to support patients, they too may generate similar disjunctures, perpetuating rather than solving problems.

In order to ensure an "everyday life dimension" (DeVault and McCoy, 2006, p.26) to the analysis presented in this and subsequent chapters, I situate Naomi's account of preventive care within her context for daily living. I start with an extended introduction to Naomi, the purpose of which is to provide a window into key elements of her life and work arising from our conversation. In presenting Naomi's account, and the disjunctures arising within it, I show various traces of the social organisation of CVD prevention, only some of which I take up in the following chapters. However, I understand these to be important elements of the context in which Naomi's prevention work takes place, and invite readers to enter into Naomi's world, to start from her standpoint as I show her work to fit prevention into her life, and discover clues to the social organisation of this work.

5.1 Introducing Naomi

I met Naomi at Wildwood Neighbourhood Centre. Census data for the local area (LSOA) in which the Neighbourhood Centre is located categorises the area as

within the 10% most deprived in England.⁸⁰ It has a relatively young demographic, with 59% people of working age, 30% under 16 years, and 10% of retired age.⁸¹ The Neighbourhood Centre Manager (Kevin) phoned me when he saw my recruitment poster, and enthusiastically invited me to attend a weekly coffee morning at which I would be sure to meet some “unhealthy specimens” who he thought would be “perfect for [my] project”. His apparently derogatory comment belied his obvious commitment to the Wildwood community — which included many years managing the centre, and ongoing efforts to attract funding for new projects and services. He explained when we met that funding was his main motivation for facilitating my access to the centre; he hoped that (in the long term), my work might show something which would help attract funding to community organisations like his.

Kevin was optimistic that the coffee morning group would talk about their health (“they’re far too open in fact!”), as long as I made it clear that I was in no way connected with the welfare benefits system.⁸² Kevin has been very successful in supporting people to claim the benefits to which they are entitled, and explained the importance of this work. I appreciated, having myself worked in the ‘welfare-to-work’ sector, that the benefits system can be extremely burdensome to navigate, and that moving between work and welfare benefits can leave a person or household in a precarious financial situation — as depicted in the evocative film ‘I Daniel Blake’ (Becker, 2017). The coffee morning was a group of about ten people, mostly in their 50s, 60s and 70s, who met in the back room of the Neighbourhood Centre. The centre provides the room, but the group is administered by Silv, a member of the group, who is in charge of the kitty (seemingly for large quantities of cheap biscuits), and who is also involved in a local community project being organised through the centre. It was clear that Silv provided a sense of support and community to the group, keeping an eye out for

⁸⁰ Data for the LSOA which includes approximately 670 households (from Neighbourhood Statistics, Office for National Statistics)

⁸¹ Reference not supplied to protect anonymity.

⁸² A large number of people in this population claim benefits associated with health: approximately 12% of adults claim disability allowance; and 18% of working age people claim incapacity benefit. Low-paid jobs are the norm, with many incomes being topped-up with income support benefits.

each individual's welfare including enquiring about ongoing difficulties and, as Naomi mentioned later "telling [her] off for putting four sugars in [her] tea".

Naomi is younger than the other coffee morning attendees and, for a 44 year old, her health is not good. She has oedematous legs (sometimes walking "like a penguin" because one leg swells up more than the other), and she gets recurrent cellulitis and gout. She volunteers the information that she weighs 22 stone — which at 5'2" height, I calculate to be a 'body mass index' (BMI) of 56 — severely obese.⁸³ She is being treated for high blood pressure and depression, and has been told that her cholesterol is also high.⁸⁴ Naomi's weight concerns her greatly for a variety of reasons, and she has been told by her doctor that, if she lost weight, she wouldn't have the other problems.

Naomi has four children, two of whom are still living at home (a teenager and a primary-school-age child, for whom she is the sole carer). She is unemployed, and her income is exclusively from welfare benefits. The Job Centre are "pushing [her] to go and get a job" but she is anxious about whether this would be sustainable - "If I have cellulitis again, and it's really bad and I take time off work, what am I going to do? Get the flipping sack?"⁸⁵ Her older children have moved to a different city to live near other family members. Naomi tells me that "when [her] daughter turns 16, then [her daughter's] money stops, and [she's] stuck"; she is relying on the child benefits income along with other welfare benefits. Naomi hates living on the Wildwood estate because of verbal abuse and physical violence to her property. Her biggest preoccupation is to move out of her current neighbourhood.

⁸³ BMI calculations are used in clinical practice to assess healthy or unhealthy weights (NICE, 2015c).

⁸⁴ She made no mention of being treated with medication for hypercholesterolaemia

⁸⁵ This scenario would leave her with the problem of having to reinstate benefits.

There are too many bad memories in [my] house. If I moved house where no one knew me, and no one knew the ins and outs of my lifestyle, and stopped poking their nose in where it is not wanted, and then I wouldn't have kids call me a fat cow. Then maybe my life would be different because at the minute it's [...] kids round my area are making my life a misery, and I have got no way of dealing with the situation, because the council won't help me, the police won't help me, and I don't even know who my housing officer is anymore, and he or she won't flipping help me to get a move. And the kids are making my life a misery [so] I can't be bothered to do anything or go anywhere or, because I ain't got no motivation. Or get up and go or whatever you want to call it.

EX2: Naomi

The kids are making Naomi's life "a misery" by for instance kicking her back gate down, threatening to hit her son with a brick, smashing her back door or throwing eggs at her window, and they shout abuse at her and her children when they go outside. She complains that other parents on the estate allow their children to stay out late at night, and don't do anything about their behaviour. Naomi has little support from family or friends. Her brother's family live locally but her brother "has problems" and has been ill for some time. Her sister-in-law is pregnant and is struggling to cope with a toddler and her husband's illness.

Embedded in Naomi's talk are many clues about how her everyday work is organised, and these include institutional processes which are separate from her interactions with the health centre. For example, her complaints that the council "won't help [her]" points to textual processes involved in the housing system — which determine who is eligible for support, on what grounds, and how resources are allocated. Naomi's personal 'health improvement' work (her general work geared to improving her health) and 'prevention' work (more specifically coordinated through the health centre) is entwined within this context — see Chapter 1. In this chapter, I focus on just one main aspect of patients' work — finding support to make prevention (and particularly lifestyle interventions) 'fit' into their lives.

Some readers may feel that I am presenting just ‘one side of the story’ in this chapter. Analysis could, for instance, highlight moments in Naomi’s account in which she engages in rhetorical, discursive work to present herself or others in favourable, or unfavourable ways (Rapley, 2008),⁸⁶ she undoubtedly uses some rhetorical latitude. However, in addressing this point, IE’s notion of standpoint is very important. Naomi’s location in relation to ruling relations is the starting point for analysis — she is an “embodied knower” who is an expert in her experience, “how things get done” (Smith, 2005b, p.24). IE’s commitment to explicating the problematic from a particular standpoint (in this study, from a patient standpoint) helps to mitigate against the production of ethnographic findings which perpetuate dominant understandings (3.5). By focusing on material accounts of people’s work, albeit impregnated with their many opinions and prejudices (see 3.7), problems which might otherwise remain hidden, are highlighted for attention. Taking a standpoint with Naomi does not negate the problems HCPs may face as they try to support her, or the extensive work of professionals to support patients with lifestyle issues. Indeed, the purpose of this analysis is to expose disjunctures in patients’ work, which will then provide clues to the social organisation of *both patients’ and HCPs’ work*. As I show in subsequent chapters, ruling relations create problems and tensions for HCPs and other professionals too.

5.2 Shifting focus from immediate stress, to risk factors, to future catastrophe

Naomi’s immediate problems are overwhelming. Her everyday life work is orientated to dealing with everyday stresses and difficulties - for instance, how to manage the kids and their parents with whom she has such strained relationships, and whom she cannot simply avoid by moving house or changing routines.

⁸⁶ E.g. from discursive psychology or conversation analysis traditions.

Informant: I pick my son up from school, we walk home, I get to near the shop and it's 'fat cow', 'ginger nut' [from the kids on the estate]

Interviewer: Are they horrible to your kids as well?

Informant: Yes. And I don't want that every time I go to the shop.

Interviewer: No

Informant: And then the woman next door but one, she is like always poking her nose in as well, in my business whatever I do. Whatever I talk to my kids about on the way home she goes and gossips and put it on to someone else. I don't want that [...]. To be honest, sometimes I am terrified of going out my own house.

Interviewer: So the whole issue about dealing with your weight ... that feels like it's just too big a thing to even start because you are feeling so low about everything else?

Informant: Yes. If I lost weight then I'd probably have a bit more confidence in myself. I don't want my kids to be ... [pause], I don't want to die. I don't want to die this age, while my kids are still young.

Interviewer: You want to be there for them.

Informant: ((gets upset)).

EX3: Naomi

Naomi has been seeing her GP regularly about her high blood pressure and various other complaints including depression. She described how the GP has emphasised that if she was not overweight, she would not have the other problems. Her response is “No shit, Sherlock, you’re clever”, “10 out of 10 for observation”. The GP is highlighting her weight as the main cause of her problems. In EX3, I too interrupt Naomi’s talk about her immediate problems with the woman next door, to bring her back to the issue of her weight as a CVD risk factor. I recognise in my question that it may be too difficult for Naomi to contemplate addressing her weight, but my interjection also reflects an institutional understanding (derived from a knowledge of risk management) that

her weight is her central problem.⁸⁷ My question jars with her most immediate concerns about her housing situation and the bullying and abuse she is experiencing. More generally, Naomi's immediate needs, for example to survive daily tasks whilst feeling low or being bullied, were prominent in her account, and they clashed with the future focus of my questions about her risk factors.⁸⁸

For Naomi, even her immediate health problems (e.g. cellulitis, depression) take a back-seat compared to difficulties relating to her relationships in the local community. Longer term risk associated with her weight or blood pressure are even less pressing, though they trouble her greatly. When Naomi says "10 out of 10 for observation", she is pointing out that it is easy for the GP to highlight her weight because it is so clearly visible. Her social circumstances are not, and so such consultations with the GP serve to single-out and individualise Naomi's problems as *originating with her weight* (and dietary choices) rather than recognising the broader context of which her *weight is a consequence*. Her body (itself represented by BMI) stands in for her social circumstances. The GP 'reads' her appearance (or the weight measurement on the scales) and reformulates it into an instruction that she needs to work harder at losing weight (because it is causing her so many other present and future health problems).

Whilst Naomi's GP works to emphasise the importance of losing weight, Naomi conversely has to work hard to shift focus from her immediate and pressing problems, to the problem of her weight as a medical concern, and onwards to the spectre of a future personal catastrophe. When I ask Naomi about her ability to address her weight, for instance, she at first thinks of the benefits of losing weight to her confidence (presumably to deal with the problems she is describing) but then shifts her focus to the implications of her current weight and health problems — "I don't want to die this age". For Naomi, shifting focus brings with it further

⁸⁷ She also identified weight as being her main problem when I showed her a list of issues which the health centre consider to put her 'at risk'.

⁸⁸ When writing my patient information leaflets, I was aware that I was using institutional concepts of 'risk' which would not necessarily resonate well in interviews, but used these terms to help me quickly anticipate fruitful areas to explore – within a huge potential terrain. After identifying 'risk factors', I always guided the conversation back to informants' lived experiences of healthy living or interacting with the textual processes involved in the identification or management of risk factors / conditions.

concerns, for instance, about who would look after her children if she died. The mental and emotional work of imagining, and taking responsibility for, this possible future catastrophe is difficult to bear, and precipitates obvious upset during our conversation.

Naomi's account reminded me of Warin et al.'s (2015) observation that people with immediate and overwhelming problems have 'short horizons' and that health promotion messages about long-term risk therefore fail to resonate with them. The metaphor fitted Naomi's account, and yet, it was quite clear to me that Naomi recognised that she was likely to suffer from future disease as a result of her current 'risk factors' — when prompted, she could see over the horizon and she dreaded what was in store for her there. Although her horizons seemed short, preventive messages have reached her. Hidden from her interactions with the GP, however, is her work to shift her focus in line with prevention's future focus, to absorb these 'at risk' messages with limited support or personal capacity to act on them. The GP's work to compel her to think ahead (to activate a risk management discourse based on 'lives saved'), well-meaning as it may be, reaches into her everyday life in a macabre way.

5.3 Trying to have a conversation

Naomi regularly tries to make appointments for various symptoms, which stem from the social difficulties she is experiencing. The health centre is the obvious place to go when, as she says, "the council won't help me", "the police won't help me", "I don't even know who my housing officer is anymore". Her various health problems therefore lead her to regularly seek support from the GP.⁸⁹ However, getting an appointment involves the tricky work of negotiating the appointment system, and it is difficult for her to get one when she feels she needs it.

⁸⁹ I pieced together from our conversation and from my knowledge of the health centre's practices that the health centre tries to ensure that she has regular contact with the same GP due to her uncontrolled hypertension, and because of complexities relating to her other health problems.

"I rang up today, and I asked 'you got any appointments for today, for me and my daughter?' 'No, it's all booked up today, you'll have to get in for in a fortnight'. Or 'you can ring up in the morning at 8 o'clock'. If you ring up in the morning at 8 o'clock it takes half an hour to answer the flipping phone [...] so that's 8.30, and then it's 'can I book an appointment?', 'Oh we are all booked up today sorry'. What's the point of ringing at 8 o'clock then?"

EX4: Naomi

The issue Naomi describes here will be familiar to most health centres and their patients.⁹⁰ Although health centres have been under pressure to improve their appointment systems, long phone queues are commonplace (largely due to capacity issues). After the trouble of getting an appointment, Naomi then experiences what she perceives to be a problem with the GP's attitude to her. The following excerpt follows from Naomi telling me that she struggles to follow the dietary advice she has been given, and that she is feeling hopeless and unable to do anything about it. As her attitude to the GP is clearly hostile, I ask her whether she thinks the doctor 'cares' about her situation.

⁹⁰ The 8am 'phone lottery' (Boyle et al., 2010) has been controversial in general practice, particularly following the introduction of a 48 hour access target which had the unintended consequence of making it more difficult to book advance appointments

Interviewer Do you feel that the doctor cares about it?

Informant: Don't think doctor cares anyway to be honest.

Interviewer: So they don't want to check up on you in a few weeks' time, or help you talk to you about how to deal with the motivation issues ...?

Informant: Well yes they do, but you can't sit down and have a long conversation with the doctor. It's oh just, 'here you are, do this, this, and this, and you have this, and this, and this, and do this, this and this'. And then it's, 'there you go I have got to see another patient now'.

Interviewer: So you feel as though you've just kind of been rushed through.

Informant: Yes, it's just 'sit there', 'what can I do for you?' Open my mouth and then it's, 'I'll give you some piece of paper' and then [they] go, 'yes come back in so and so'.

EX5: Naomi

When Naomi gets to the GP, she thinks that she needs a conversation about the problems she is facing in addressing her weight, but the GP seems to be working to stop Naomi in her tracks when she starts to talk — she gets as far as “open[ing] her mouth” and is cut short. As a result, she “can't sit down and have a long conversation” and tells me later that she “just need[s] to talk to someone” because she “can't see the light at the end of the tunnel”, and to prevent her “going insane”. To add insult to injury, the GP converts her appeal for a conversation (to include her everyday ‘social’ issues) into “a piece of paper” containing dietary advice, or as “eat less, go for walks”. Naomi's work not only includes trying to engage her GP in conversation, but then keeping quiet while the GP reconstructs her needs into standardised, and simplified, lifestyle advice. In doing so, the GP fails to recognise Naomi's desperation, and her efforts to address her weight (unsuccessful as they may be). Naomi is given little opportunity to ‘answer back’, to question, to explore what options are realistic, what she has tried, what the problems were, and how she may find a good practical way forward. Here Naomi is looking for a different kind of access to that which has been an ongoing concern of policymakers (e.g. Boyle et al., 2010); she looks not just for physical and timely

access to general practice services (although this is a source of great frustration), but also for a ‘conversation’ when she gets to the appointment. As my analysis progresses, Naomi’s frustration at not being able to have a ‘conversation’ becomes a disjuncture out of which I develop the problematic for this enquiry.

Patients frequently alluded to the type of interaction above and, according to Naomi, the pattern repeats itself regularly when she sees her GP — even though, in Naomi’s case, she has some ongoing contact with the same individual. HCPs in turn often referred to this standardised delivery of information and advice as good clinical practice. This work, they said, nudged patients, reminding them of what they should be doing without pressurising them. In policy language, it was “Making Every Contact Count” and was the authorised response to Public Health England’s call to “all health and care professionals” to “get serious” by “[embedding] and [extending] prevention, health protection and promotion of wellbeing and resilience into practice” — branded as ‘All Our Health’ (Bennett, 2016) (see 4.1). However, the presentation of advice as *simple* clashes with what Naomi knows would be involved in making significant lifestyle changes — e.g. working out what to eat, dealing with hunger and depression, or how she would ‘go for walks’ without being subject to abuse for “walking like a penguin” (5.1). It is worth noting here that the preventive activities which are entering into Naomi’s interactions with HCPs (including initiatives such as MECC and “All Our Health”) are organised within an institutional complex which includes an array of textual processes. I briefly outline two aspects of this complex here, as they are important context to some other concerns addressed in this and subsequent chapters.

First, efficiency is promoted through the rationing of time; the health centre operates using standardised appointment times which determine how HCP time is booked. At Wildwood health centre, this included 10 minutes available for routine GP consultations, 20-30 minutes for nurse-led chronic condition appointments, and 30 minutes for a Health Check appointment (Interviews and Fieldnotes). When Naomi tells me that the GP cut her short and simply provides

her with instructions when she starts to speak, I recognise that the GP is working within a time allowance, even if some flexibility is usually exercised.⁹¹

Second, services are ordered so that Naomi's needs are organisationally divided into 'health' needs (commissioned as part of the GP contract (NHS England, 2017) and 'social' needs which fall outside of the contract and may be addressed by a range of other services (primarily commissioned by the local authority) — 2.7. So Naomi knows that the appropriate place to discuss her housing issue is with the council's housing officer and to report abuse to the police. But her needs are interconnected and her prevention work (e.g. addressing her weight) involves these other problems. When she does not get help from the council or the police, she presents these 'social' problems to her GP as factors in dealing with her weight. Naomi's prevention work therefore straddles the artificial boundary between 'health' and 'social' needs. Both Naomi and the GP understand that her social situation (and her associated low mood) impacts on her ability to address her weight — and that her desire to have a conversation is in many regards 'appropriate' (it falls within discursive understandings of 'health' care, and within the GP contract). However, this is a grey area.

In my observations and interviews, HCPs frequently spoke about which problems they were (or were not) able to support within the time available — and expressed their frustration with the time implications of patients' 'social problems', especially those working in deprived communities. HCPs have to continually make decisions about which issues they will respond to, and the pressure to prioritise is particularly acute in the context of the current primary care capacity 'crisis' (2.7). Based on this data, it is logical to conclude that within the workforce and capacity restrictions of the health centre, Naomi's most pressing problems relating to abuse or housing fall outside the scope of what the GP considers herself to have the capacity to support as part of Naomi's routine care. The GP instead sticks to the suite of interventions which are recommended in clinical guidelines (see Chapter 4). Naomi, however, without this view of how her GP's

⁹¹ Most health centres have introduced a 'one problem per consultation' rule in order to fit their tight consultation schedule. Although GPs generally operate some discretion (particularly for the elderly with complex comorbidities), even consultation for 'health' problems is being strictly rationed.

work is organised and, experiencing the disjuncture between this institutional knowledge and her own, concludes that the GP ‘doesn’t care’.

5.4 Accepting authoritative ideas about ‘motivation’

In 5.3, I showed that Naomi tried to “have a conversation” with her GP about her life and how she could incorporate lifestyle change into it, but found that this was not possible within the institutional structures which rationed and structured appointment times. I showed how Naomi’s GP used brief lifestyle advice and information to substitute for the conversation which Naomi wanted. In this section, I consider how institutional ideas about patients’ ‘motivation’ are activated by HCPs and patients. In the following excerpt, I attempt to ask Naomi about the work involved in changing her diet. But she repeatedly comes back to her own inability to motivate herself.

Interviewer: Do you think that you know what a good diet would look like as in or do you need help with that kind of thing as well?

Informant: I wouldn’t know what a good diet was if it hit me in the face ((laughs)).

Interviewer: No ok. So it’s quite hard to actually do yourself a good diet, and figure it all out if you don’t know what that means?

Informant: No because they just give you bits of paper and go oh you can have this, you can have because to me it goes over the top of my head. I wouldn’t know what a diet was if it hit me in the face.

Interviewer: So what do you mean by ‘they just give you bits of paper’?

Informant: Well you know they give you like a diet sheet, and yes you can follow this and you can have this, and you can have this.

Interviewer: And does that not make sense to you or you just don’t want to look at it or?

Informant: Probably both. I know it sounds like I am setting out as a bad example I know but, it’s like yes I do want to look at it, and yes I want to try it, but then like, sod it I can’t be bothered. That’s how I feel.

EX6: Naomi

Naomi tells me that she has “been trying all [her] life to lose weight” but that “nothing helps”. She returns again to her grievance that the GP gives her “bits of paper” which she says go “over the top of [her] head” and tells me that she thinks “sod it, I can’t be bothered”. I try to bring some positivity to our conversation by suggesting that perhaps she is more motivated than she has suggested. After all, she had already told me that she had made some efforts, for example: attending a gym intervention (see 5.6 below); researching exercise equipment which she could buy to use at home; and cutting down the sugar in her tea. (It was clear from our conversation that, when she says that she does not know *what a good diet is*, she does not mean that she has absolutely no clue. However, she has never put a good diet into practice, and does not really know how to achieve this in the context of her budget, the shops available, her children’s tastes, and so on. Changing diet would involve a massive amount of work, for which she would need support.)

Interviewer: You sound like you are quite motivated to want to do something about it [your weight].

Informant: Been trying all my life. I just ain’t got no ‘get up and go’. It’s got up and gone.

EX7: Naomi

When Naomi spoke about why she has failed to follow lifestyle advice, she repeatedly told me that she was ‘unmotivated’ with “no get up and go”, “no mojo”. She described how she “don’t listen to reality” and “until I have a heart attack, or I drop down dead, or half drop down dead, then it will hit me”. This assessment of her situation stands in contrast to what she has already told me about the difficulties of her life, and her assessment of HCPs’ willingness to help.

Informant: It just seems to me nobody wants to help. They just fob you off. As in ... sorry for using this language but ... talk shit to you.

Interviewer: Who it is that talks shit to you?

Informant: Doctors they don't really want to help you, they just talk a load of crap to you. And then it's, yes go and do this, go and do that. It's not easy for a person. It's alright for them to say but it's not easy doing it.

EX8: Naomi

Here Naomi claims that “nobody wants to help” and that “it’s alright for them to say” but “it’s not easy doing it”. However, her experience of HCPs’ lack of support is consistently mixed with ideas about her own lack of motivation. They weave throughout our conversation, sometimes as obvious contradictions, but often appearing to be complementary. As we talk, we agree that her efforts are tinged with the disappointment of past failures — as I suggest, and she assents, she “half-tries”. However, it is her *own lack of motivation* which forms her dominant explanation for failure.

Many other patient informants talked about their poor motivation. Sarah, for example, told me that she needed more “willpower” and a “kick up the bum” to get back into healthy exercise patterns, whilst also acknowledging her struggle to make dietary advice fit into her everyday life. Although she cooked balanced, nutritious meals, her blood sugar levels were consistently higher than recommended, and she had experienced extensive side-effects of Metformin, a commonly-used to lower blood sugar levels in people with diabetes (T2DM). Although she had a bunch of dietary leaflets in her kitchen drawer, she struggled to work out how to adapt their black-and-white guidance. She wanted to understand what the “little bit of sugar on the end of a spoon” that she likes to have in a cup of tea was really doing to her body — how important was this little bit of sugar? If it made her life feel better, could it be justified?

Because the booklets don't tell you that. They tell you that you've just got to stop having sugar. But when you've had sugar for nearly all your life ...

EX9: Sarah

As a result of experiencing various health problems, including having to adjust to a diagnosis of T2DM, she emphasised that she and her husband were trying to find a “way of life” which worked for them. This was now full of complexities, including the bodily feelings of lethargy (demotivation) and side-effects of medications. Lifestyle advice about diet and exercise did not stand as discrete and separate from this everyday context.

It is not my intention here to overlook the individual, psychological, elements implicated in Naomi's, or others' compliance (or non-compliance) with lifestyle guidance. However, attending to patients' work as it coordinates with their HCPs' work helps to shed light on this disjuncture between two alternative ways of knowing – played out *within* patients' own accounts. Instead of “I can't be bothered”, Naomi, for instance, could have substituted “it is too difficult” or “the support offered doesn't work for me”. But she does not (or cannot) articulate these alternative versions. Instead, she activates an institutional discourse, which I recognise from my observations in clinical practice and from policy and guidelines (4.1). She confesses to being lazy and unmotivated, and edits out her own social situation from her interactions with the health centre. Recognising that she gets *some* (albeit very limited) support, and that she knows what she ‘should’ be doing, a ruling discourse of ‘motivation’ takes over. The language of ‘motivation’ is created as what Smith (Smith, 2005b, p.95) calls “interindividual territory [...] anchored in texts” — a discursive link passed from the GP to Naomi. She takes this up and applies it to her everyday context.

5.5 Improving patients' motivation

As discussed in 4.1, and in 5.4 above, ‘motivation’ is a dominant discourse in general practice. Linked also to appeals to ‘engage’ or ‘activate’ patients, HCPs consistently discuss their patients' poor motivation and their own limited ability to impact on this. Although I found this concern to frequently be linked to patients' difficult social circumstances, or to other complexities in their everyday lives, the

main interventions available to HCPs are aimed at addressing individual motivation. As outlined in Chapter 4, guidelines are increasingly encouraging commissioners to train HCPs in ‘motivational interviewing’, and one of my informants (Christina, Health Care Assistant) enthusiastically told me about her experience of attending such training. Intrigued by her enthusiasm, I arranged to participate in a training day myself. This brief section is based around my conversation with Christina and my experience of attending the training.

Motivational interviewing is promoted as a technique in which HCPs guide conversations so that patients “talk themselves into change, based on their own values and interests” (Miller and Rollnick, 2013). It is appealing for its simplicity and for its focus on patients’ own self-care (see 4.1). Starting from a patient’s own talk (often containing negative statements about their ability to make changes), an HCP uses a prescribed process of questioning, affirmation, and summarising in order to encourage the patient to take a small step towards implementing positive behaviour change. It claims to bring optimism and positivity to patient interactions — considered especially useful in changing intransigent lifestyle behaviours. Key to motivational interviewing is ensuring that the ‘responsibility’ for lifestyle remains with the patient. On the training course I attended, this process was illustrated by passing a toy monkey to ‘the patient’ during role-play. The toy monkey was used as a metaphor for the problems and obstacles that patients bring to a clinical consultation. Christina, following the example used in training, characterised patients as “giving all their monkeys” to her. Using motivational interviewing, she understood that she could ‘gently’ and ‘compassionately’ pass the monkeys back to her patients as she helped them to reformulate these into practical intentions. The approach made sense in the light of the time-constraints of the consultation, and HCPs’ limited skills in counselling patients. Having previously felt overwhelmed with patients’ problems, Christina found this approach to be liberating.

Although I was unable to observe HCPs employing this structured motivational interviewing technique in routine clinical practice, its increasing influence was evident at conferences, on social media, and from conversations with HCPs. It offered some clear benefits in terms of promoting a positive dynamic with time-constrained appointments. However, its simplistic basis (that patients’ unhealthy

lifestyles (or, in Sarah's case, abnormal biomarkers) were underpinned primarily by poor motivation) clashed with patients' knowledge about the complexities of their lives and of integrating lifestyle guidance.

5.6 Building relationships through intensive lifestyle interventions

Having discussed Naomi's experience of lifestyle support at her health centre, I now show what happens when patients are understood to have serious lifestyle risk factors, which require more 'intensive' support. Naomi, for instance, told me that she had previously been referred by her GP for some free sessions at the local leisure centre (gym) to help her lose weight (an example of what is known as a 'lifestyle intervention' (4.1). She attended for a few weeks but then dropped out in part because she was embarrassed about the difficulty she was having using the equipment, and about her appearance in public. In English-region, as in others, local commissioners have increasingly funded these lifestyle interventions. As several HCPs (e.g. Sergei, Annette) pointed out to me, GPs do not have time within the course of routine clinical care to adequately address complex lifestyle needs such as Naomi's (i.e. those which are considered to require more than a 'brief intervention' or 'advice'), and the HCPs need to have something more intensive to offer their patients, especially following attendance at a Health Check (see Chapter 4).

Although commissioners have some latitude about the format and range of services they offer, they tend to prefer widely-accepted 'evidence based interventions', even though they understand the evidence for some of these to be weak or limited (interview data). In English-region, a new Lifestyle Control-centre⁹² had recently been commissioned from a commercial provider. This was not a new intervention but it aimed to rationalise the referral process, making it simpler for GPs as it only required them to fill out a single (short) referral form — this was then sent to the control-centre electronically. The control-centre's main functions include: maintaining an up-to-date log of services' eligibility criteria;

⁹² The name of the service is pseudonymised.

completing an assessment of patients'⁹³ “holistic” needs and referring them onward to appropriate services; and completing relevant administrative processes including submission of data returns to commissioners (various informant interviews and service documentation).⁹⁴ Services to which the control-centre advisers referred include: Weightwatchers; Stop Smoking Service; Leisure Centre Intervention; Alcohol Support; and Health Trainer Service.⁹⁵ Both the control-centre, and lifestyle services, are competitively commissioned⁹⁶ to organisations that submit contract proposals for services; once the contract is awarded, the organisations that are funded must operate according to service specifications which define their contractual obligations and payment schedule — the contracted organisations are paid based on a ‘payments-by-results’ system. Examples of the types of outcomes rewarded include, for example: number of people referred; time taken for them to contact the individual (control-centre); number of ‘Plans’ completed (Health Trainer Service) (interview with Tanisha)⁹⁷.

In the rest of this section, I focus particularly on the Health Trainer Service, as it is designed to motivate patients to make exercise and dietary changes (and is therefore relevant to the themes pursued in this chapter). The data presented here are based on an interview with Tanisha, a health trainer who was also involved in managing the organisation that won the award to provide the service. According to Health Education England (2015), health trainers “help their clients to assess their lifestyles and wellbeing, set goals for improving their health, agree on action-plans, and provide practical support and information that will help people to change their behaviour”. Tanisha explained that the health trainer intervention usually involves a series of six 30-45 minute, one-to-one sessions

⁹³ Following referral to the Health Trainer Service, the patient is known as a ‘client’. Here however, I maintain the term ‘patient’ for continuity, except when using direct quotations from Tanisha.

⁹⁴ Citation omitted to protect the identity of the provider.

⁹⁵ Generic names used here to support anonymity.

⁹⁶ Although, as this is an emerging market, competition is not always very strong (interview with Annette).

⁹⁷ Service specifications were not available due to ‘commercial confidentiality’.

over the course of 3-6 months. In the following excerpt, Dr Abel tells me about the importance of such services in ‘motivating’ patients.⁹⁸

[The problem is] getting through the hurdles to get [patients] there. Once they are there, they can build up their relationship with the trainer. Or, if they are in a group class, some people they may get on with, and they then feel more motivated. But it's actually getting there is the biggest hurdle for them really.

EX10: Dr Abel

Although Dr Abel has no first-hand experience of these services, she interprets their value from how they are represented in policy and the local health community, and therefore understands the Health Trainer Service to be a good way for patients to “**build a relationship**” with the trainer — as a result of which they will be better motivated. As other HCP and policymaker informants pointed out, the dedicated appointment time available through this service should make this possible. Still applying the motivation framework, Dr Abel considers that the biggest problem is ‘getting her patients there’ — persuading (motivating) them to attend.⁹⁹ After that, their ‘lifestyle’ needs should be catered for and she can focus on their ‘health’. Getting patients to the Health Trainer Service is indeed difficult. Many patients agree to be referred to the control-centre but then do not follow through. Often the control-centre is unable to contact them, or they drop out before the lifestyle ‘intervention’ is completed. Somehow, it seems, the intervention does not ‘fit’ well with their lives. My attention was drawn to clues in the data about the social organisation behind the drop-out rate. I noted aspects of the process of assessment, and also the fragmentation of the various interventions involved, that seemed in tension with the concerns I had learned from patient informants — both those who were ‘motivated’, such as Dan, and those who were not, such as Naomi. I discuss some of these now.

⁹⁸ Dr Abel mentions a ‘group class’, which refers to structured education on the management of diabetes which is commonly delivered in groups.

⁹⁹ Low referral rates to the control-centre were a concern of local policymakers.

A patient's first contact with a lifestyle intervention such as the Health Trainer Service is over the phone with the control-centre in which their lifestyle and eligibility was initially 'assessed' (e.g. "how many fruit and veg, do you drink alcohol, do you smoke", do they live in the right area for XYZ intervention? (Tanisha)).¹⁰⁰ The process requires that the person referred then had to arrange to meet an unfamiliar health trainer, often at an unfamiliar location.¹⁰¹ If the patient then presents at the training centre, their 'bad' lifestyle undergoes further scrutiny during an assessment with the trainer and they are required to *agree* to lifestyle goals. Like Dr Abel, Tanisha told me that this questioning, about basic aspects of lifestyle, gives the health trainer "a chance to get to know [the client]". However, experienced by the patient, responding to the trainer is a repeating loop, consisting of the same, or similar, set of mundane questions. (Patients frequently referred, directly or indirectly, to these basic lifestyle questions.) For patients, such as Naomi, those aspects of their lives that are already stressful come under the close scrutiny of these official institutional frameworks. For many attendees at 'lifestyle interventions', whose lives are organised by poverty and co-morbidities related to obesity, this may be experienced as another way of being subject to affronts not dissimilar to "fat cow" and "ginger nut" (EX3). At the outset of the lifestyle intervention patients' failures are emphasised — likely those features of their lives that are emotionally difficult and that reinforce their sense of themselves as having "no get up and go" (EX7). These experiences, although framed as 'getting to know' the patient and 'building a relationship', are driven by textualised forms of lifestyle intervention, and seem unlikely techniques for having the kind of conversations which patients need to support them with making difficult lifestyle changes.

Nonetheless, the people working at the Health Trainer Service *do* at times work closely with people and, despite the assessment tools they must complete, relationships develop and some patients *do* respond to the lifestyle strategies

¹⁰⁰ Due to local commissioning arrangements, they might find that they were not eligible for the service in which they were most interested,

¹⁰¹ Tanisha explained that having a centralised control-centre made things run efficiently but could create problems when the operators did not know the bus routes.

they are offered. This is evident in Tanisha's description below of how she adapts her intervention to each patient's particular needs.

For someone who maybe can't read or write, when we ask them to do a food diary, we could ask them to take photos on their phone. [...] I worked with a lady who lived on her own, she was pre-diabetic and not eating healthy food [...] so we went round the shops looking at labels, and I said 'well you're not going to change your ready-meals so we'll see if we can find you some healthier ones'. And within those three sessions she swapped her ready-meals and lost 7 pounds and she was no longer pre-diabetic. So little things can really make such a big deal.

EX11: Tanisha

Tanisha relates this as a story of personalised care which led to successful lifestyle change — albeit that she could not have known whether this success was maintained. However, Tanisha went on to tell me that this style of individualised support is becoming more difficult to incorporate into health trainers' work as the centre is increasingly orientated towards hitting targets. In the provision of the English-Town/County Health Trainer Service, targets relate to the creation and fulfilment of patients' individualised goals within their personal Plans. This is the institutional purpose of the 'agreement' that is reached during the assessment phase.

The provider's contracting team had ensured that the contract provided financial compensation for the attainment of goals which would be readily 'achievable'. The easiest goals to measure are things such as increasing the number of steps walked per week, or decreasing waist or clothes size. Other measurable goals which are deemed harder to realise (but which were more valued by commissioners and therefore also included in the contract) include the 3% weight loss target. In any case, the provider reports on the percentage of clients who reach their personalised targets as encapsulated in their Plan:¹⁰²

¹⁰² Figures in this excerpt are redacted.

We have a target around how many people achieve their Plans. So you have to get [XX]% partially achieving, and at least [XX]% fully achieving. So we have to be very careful around the goals that we set and make sure that it is realistic. [...] If it's just weight-focused, then if they don't lose weight it can be quite demotivating. And it's not a very successful Plan.

EX12: Tanisha¹⁰³

Despite the fact that the language of ‘agreements’ and personalised plans are integrated into Tanisha’s conceptual understanding of her work, the traces of what she knows constitutes a “successful Plan” from an institutional perspective are significant to her practice. An institutionally successful Plan is one which will *maximise the chances of measurable achievements*. The importance of these outcomes coordinates Tanisha to set very modest goals which patients will find easy to achieve (frequently measured through patient self-reports). This, Tanisha says, supports patients’ motivation — after all, it enables a sense of achievement — but it is also a sensible commercial arrangement, as it will enable the service to demonstrate its success to commissioners and achieve maximum profitability. The service’s profitability is not only based on patients’ ‘results’, but also on *keeping costs low* by employing trainers with entry-level skills on low hourly rates. Tanisha told me that they sometimes struggled to recruit because of hourly rates which were only a little above the national minimum wage, and because trainers usually needed to use their own transport. The training roles require little formal education or training; although staff complete some basic training on starting the role, it is not necessary for them to be particularly knowledgeable about nutrition or exercise, as their job is to stick closely to government guidelines for healthy eating and weight loss:

¹⁰³ Numbers are redacted for reasons of commercial confidentiality.

You don't need to know a great deal. If you're asking the right questions, it's relying on them, they're doing the work for you. In a way, I think it's probably more beneficial that [health trainer] knowledge around things like nutrition is not so wide. So then they are sticking to the information that they should be. Because it's a fine line between the health trainer role and going beyond your boundaries in terms of being a nutritionist. You have to be really careful.

EX13: Tanisha

For some patients however, this rigid observance of government guidelines, organised around keeping costs low, appears to create some tension. As described in 4.1, recent years have seen controversy over healthy-eating guidelines, particularly the Eatwell Guide. This controversy is not confined to the clinical-academic community, but spills over into the media and into patients' knowledge of healthy living.

We get people who say I'm not going to eat carbohydrates because that's making me put on weight. You will hear this from patients. You hear that coming out, some really odd things. A lady wouldn't eat a banana before a certain time, and that was all down to some controversial stuff that was out there. People are reading and getting mixed-messages all the time.

We might use the British Dietetic Association [resources]. We stick to reliable sources. We don't get to do complicated information so, for example, if the person's got diabetes, we won't focus too much into that region, we'll focus on 'are they eating their 5 a day and reducing their fat intake?' We're not qualified to that degree so we try and be careful.

EX14: Tanisha

Tanisha points out that some patients claim that carbohydrates are making them put on weight — an insight that seemed relatively uncontroversial to me, as it is well documented at least in some authoritative sources relating to weight loss. However, because these ideas deviated from a simplistic interpretation of the (already simplified) dietary recommendations captured in the Eatwell Guide, Tanisha characterises these patients' dietary attempts to be ill-informed

misconceptions which should be ironed-out; as the Eatwell Guide recommends that one third of a person's diet should be carbohydrate, this is what she (and they) should stick to, even though the client is attempting to lose weight. She emphasises that health trainers must "be careful" not to stray into professional territory by proffering or condoning unauthorised knowledge. As a result, they stick rigidly to information from narrow and simple "reliable sources" such as the British Dietetic Association¹⁰⁴ and correct any practices which fall outside of its standardised knowledge. This, according to Tanisha, even includes dietary adaptation for people with particular metabolic needs (e.g. diabetes). Although the approach from the Health Trainer Service could be considered to follow basic understandings of good dietary advice, the potential for that advice to clash with patients' own knowledgeable attempts to improve their health emerges as another tension embedded in the social organisation of these services. From my conversation with Tanisha, it appears that such services can only offer the most basic of advice and cannot usually support the more nitty-gritty work required to implement major changes.

Only two of my informants had attended a health trainer intervention. Sharon, who had completed an intervention, told me how she had valued the encouragement provided, but that this support had only been available for six months — she had been upset when it finished, feeling as though she were back to "square-one". In cases like hers, health trainers find that they have to address a tension between patients' ongoing needs (and the lack of flexibility to accommodate them) with the short-term packages commissioned and funded. Once a patient has completed (or failed to complete) the intervention, they are then no longer eligible for re-referral. For this reason, health trainers need to ensure that patients understand the limitations of the intervention and they reinforce messages that patients' prevention work is *their own responsibility*.

¹⁰⁴ There is not space here to explore the role of organisations such as The British Dietetic Association (BDA). However, the BDA has come under considerable criticism for its links to the food industry (e.g. Malhotra, 2013b). I also noted that at several of the directors of the Health Trainer Service were connected to the food industry. Another, describing herself as a 'nutritionist', maintained a Twitter feed which was largely devoted to the promotion of low-calorie, low-fat branded food products.

Tanisha describes in the following excerpt how this is understood as an effort to “empower” them to make and sustain changes.

You do have to be careful that people aren't relying on you for support because what we want is to empower that person to become their own health trainer and to set goals themselves and continue to work on things. We don't want people to become dependent.

EX15: Tanisha

With the advent of publicly contracted lifestyle interventions, patients are increasingly referred out of general practice for support. There may be little connection between what happens at the health centre and what happens at a lifestyle intervention. Although GPs like Dr Abel may think that patients have the chance to “build a relationship” (EX10), my data suggest that this opportunity is very limited. Even if patient and trainer strike up an immediate rapport, the trainer has to ensure that patients do not become too “dependent” (EX15). Patients also have to cope with being passed between different interventions, perhaps working to form multiple relationships in order to generate supportive care, or perhaps giving up and dropping out. Although the GP or another HCP at the health centre may provide some continuity, this is by no means guaranteed within the (increasingly corporate-like) operation of general practice and, as the next two chapters show, is unlikely to be based on an established interpersonal rapport. In short, none of the services in this network of actors and interventions appears likely to provide the kind of sustained support that patients like Naomi seek.

5.7 Being abandoned

Throughout this chapter, I have shown how lifestyle interventions, steeped with ideas about patients' need for ‘motivation’, clash with patients' own appeals for a ‘conversation’ about their needs (EX5) and for ongoing, individualised support. Using psychological notions of motivation and behaviour change, health trainers and HCPs understand themselves to be helping patients find their own solutions to lifestyle problems by envisioning a better future for themselves, setting and reviewing goals, and becoming ‘engaged’. They anticipate that patients will be inspired to work steadily towards an improved lifestyle in line with accepted

guidance. As I have shown, however, patients' knowledge of what they need is sometimes (perhaps frequently) at variance with this institutional knowledge generated within conceptualised ideas about lifestyle change; making such lifestyle changes is often seriously at odds with people's actual style of life, and is neither simple nor entirely dependent on their inner motivation. While ideas about 'motivation' as a psychological concept are *part* of what informs people's capacity to adopt new habits, I have shown that patients' knowledge of their needs is a far more *practical concern* than positive psychology can address. People like Naomi look instead to experience a down-to-earth conversation through which they may receive help to incorporate lifestyle change into their lives — for example, how to manage the everyday details of what foods to buy, how to cook them, how to afford them, and crucially how to find the best compromise between an ideal scenario and one which is possible in the light of life's many difficulties and unpredictabilities.

As introduced in Chapter 3, Mol's (2008) logic of care is congruent with the ethnographic data and institutional analysis being built in this chapter. Within Mol's development of this logic, care is an ongoing process, requiring adaptation and persistence as patients and HCPs work together. In this analysis I am placing an ethnographic magnifying glass onto how such an ongoing process is subordinated to the ruling relations of contemporary health and social care organisation. As I am showing, despite a compelling rhetoric of 'relationship building', practices of care (as conceptualised by Mol) are systematically omitted within the ruling relations of textually standardised lifestyle interventions. Although the analysis in this IE shows that some HCPs and lifestyle professionals manage to incorporate practices that *do* have the character of Mol's logic of care, my data suggest that lifestyle interventions, and preventive practices more generally, cannot usually be characterised in this way — this style of practice is not the norm. Within dominant practices of 'support', patients with unhealthy lifestyle habits are drawn into 'motivational' practices in which they may be compelled to articulate again and again their lifestyle failures, and to visualise a better future (that will reduce their future 'burden' on the system – see Chapter 2), but with little practical help to achieve that better future as a reality in their own lives.

Of course, some patients *do* manage to make lifestyle changes — with, or often without, the intervention of services such as the Health Trainer Service. Dan appears to have done this very successfully; following a prompt from his GP, he managed to transform his own lifestyle through educating himself about food and nutrition, and then found ways to apply this knowledge in practice. He had found some motivation, and had the resources (the skills, the time, the internet) to make changes. However, a key element involved in his motivation was to improve the overall quality of his life and to *avoid taking so many medications*. His ambitions did not conform to the institutional knowledge on which his GP was drawing and, as we saw in Chapter 1, this clash generated problems. (I come back to compare Dan's situation in 5.8 below.) There is a possibility that some may thrive under the knowledge practices built into interventions for lifestyle change. But my analysis suggests that only a few will experience no difficulties with implementing standardised forms of preventive intervention into their lives; it is far more common that patients experience health and social challenges such as those faced by people like Naomi. Although many patients manage to engage their own network of resources to improve their health (finding people to support them, to access and make sense of information, to do the emotional work of processing it all and applying it into their own everyday life), Naomi, with little ability to care for herself, and apparently no support within her social network, continues to desperately persist to seek care at the health centre. Not only does she lack the education or emotional resources to do the work which would be involved in making prevention 'fit' into her life, but she also realises that she has limited support from others around her to step in to help her fill this void.

Karen, an experienced Practice Nurse, summed up the essential resource of supportive relationships during a conversation about her frustrations of trying to support people to manage their diabetes. She described two different patients, one who had apparently followed her advice about managing his diabetes, and the other who had not, and had consequently required a limb amputation — describing this second patient as 'not engaged'. In the following excerpt, Karen responds to my question about whether, in her opinion, 'social issues' (already referenced by Karen in our conversation) are to blame for his disengagement:

Interviewer: Is it because of all their social issues that people just can't or won't engage?

Informant: I would say they... The only difference is that the guy that's had the amputation is not in such a happy relationship perhaps, than the other one, with his wife

Interviewer: That's something you don't pick up normally in research, is it?

Informant: No, but you pick it up in this job

EX16 Karen

I highlight this conversation as I conclude this chapter because Karen has many years of working with patients with diabetes, yet her knowledge of the relational support required to make and sustain lifestyle changes does not appear within institutional structures designed to manage risk conditions. Although we can only guess at the care practices within this man's "happy relationship", it seems reasonable to imagine that it involved ongoing, persistent "tinkering" (Mol, 2008, p.14) with diets, blood sugar measurements and so on. Karen knows that her patients need this, and to some extent she is able to adapt her appointments to support them, but her knowledge is organised. Although she 'knows' that the guy with the amputation probably needed more support, she was unable to offer it within the institutional structures organising appointments times and the highly choreographed activities she is required to undertake (see Chapter 6/7). People who do not have personal networks of support, for whatever reason, are likely to struggle when care is left out of healthcare services.

Naomi's experience resonates with Mol's (2008, p.98) description of people feeling abandoned: "*The point is not that others boss you about but that nobody cares. A hole opens up and you fear that you will fall right through it.*" Similarly, Naomi tells me, she "can't see the light at the end of the tunnel". This chapter begins to build an analysis about how that "hole" is socially organised. Despite the considerable resources being directed towards improving the health of people like Naomi, those improvements are being developed within the **conceptual frameworks** of, for example, 'prevention', 'motivation', and 'engagement' — ruling abstractions, separated from the actual lives of real people, which are built

into policy, funding, and HCPs' practices. Other traces of ruling relations are also evident in the accounts presented in this chapter. For instance, we begin to see how lifestyle interventions which are organised to fit into the time constraints of frontline clinical practice and around textual constructions of cost-effectiveness (see 4.1) enter into patients' lives. We see how lifestyle programmes may offer more of the same standardised questions about, and solutions to, people's health needs to those promulgated in routine clinical practice — entering into patients' lives as naïve and/or humiliating. Within these arrangements, we can begin to see how Naomi's 'abandonment' is a direct consequence of the social organisation of prevention, and amplifies the lack of supportive and relational 'care' in her own social network.

Of course, people's social networks are unlikely to support many of the complexities of preventive interventions, such as managing medications. However, people with non-medical skills who are willing and able to help with adaptive 'tinkering' work to fit preventive activities into everyday life are important. The Wildwood Community Centre and other enterprises, such as Wildwood Social Club¹⁰⁵, attempt to promote friendships in this deprived area, but they operate with minimal resources which are under threat. Although such provision cannot provide the individualised intervention and medical know-how from which some people will benefit, they do facilitate relationships which provide ongoing support with the ups and downs of daily life. For Naomi, the Wildwood Social Club, being focused on older people, was not a suitable option. But the huge need for ongoing relational and practice support was evident from such initiatives. HCPs trying to support patients like Naomi are faced with her failure to sustain successful lifestyle change and, within the institutional structures organising lifestyle support through the health centre (and in the light of the lack of support in the community) they are left with few options. Her GP focuses on the CVD risk factors which she thinks she can most easily influence:

¹⁰⁵ A community effort initiated and run almost entirely by an unpaid member of the community.

Informant: I [spoke to the doctor] about wanting a gastric-band. I know it's a big decision and it's a very big move, but I've got to do something. I can't carry on like this anymore. But all she said was 'have some tablets'.

Interviewer: Tablets?

Informant: Because I've got high blood pressure. 'Here, have some tablets'.

EX17: Naomi

Although it is clinically-indicated for the GP to prescribe antihypertensive tablets to Naomi, Naomi understands them as substituting for the care which she needs. At the time of our conversation, she had been on tablets for high blood pressure for about five years. She says she “hate[s] taking tablets” mainly due to the headaches they cause, and because she “hate[s] taking tablets altogether”. To make things worse, she says the tablets are not doing anything (not bringing her blood pressure down enough).¹⁰⁶ When I ask her why she takes the tablets if they are not doing her any good and they give her side-effects¹⁰⁷, she explains “if I didn't take them, I'd get told off”. Although Naomi understands that blood pressure medication is important to bring her blood pressure down (another risk factor that she says “could kill [her]”), the tablets themselves, and the apparent ease with which the GP prescribes them, represent to her a failure in care. Unlike Dan, Naomi does not have the ability to take her health into her own hands, so she tolerates the side-effects of these medications in an attempt to maintain some kind of a relationship with her GP — and to keep open the elusive possibility of a ‘conversation’.

5.8 Refining the study problematic

In this chapter, I have shown various tensions as people's health and social needs come up against the social organisation of prevention (and particularly as they try to ‘fit’ ‘lifestyle’ interventions into everyday life). Here, I am rolling these

¹⁰⁶ I did not ask Naomi about the detail of her medication taking, so it is unclear how reliably she is taking her medications. What is clear is that her blood pressure is still “very high” and she is therefore being closely monitored by the GP.

¹⁰⁷ The GP reportedly says “here's some paracetamol” when Naomi reports side-effects.

disjunctures together, and highlighting a “bigger problematic”, based on the “formulation and explication of small problematics” (Rankin, 2017a). This chapter has focused on Naomi, her knowledge of her own needs, and the ‘lifestyle’ interventions which are positioned institutionally to support her. Dan’s situation is very different to Naomi’s, yet it is possible to see similarities. In Dan’s case, he struggled with preventive medications (not ‘lifestyle’ change), but he too had told me that “*there was no meaningful conversation between the two parties — it was ‘you will, you must’*” (EX1). In the absence of being able to generate a constructive conversation with his GP, he too had come into conflict with the ruling relations organising preventive care.

Based on the congruence I saw between patients’ knowledge of the support they needed to improve their health and Mol’s (2008) descriptions of good care practices, I suggest that Naomi and Dan’s attempts to have a ‘conversation’ are appeals for adaptive, and ongoing ‘care’ which responds to their own individual situation and limitations (see 3.3.2). As I will show in subsequent chapters, it is not just Naomi and Dan, or people from economically disadvantaged situations, who appeal for this type of care. The problematic therefore asks “how is it that patients’ appeals for care frequently go unheard within the social organisation of preventive care?” This question, and others related to it, guide the analysis in the following chapters and develop the problematic previously ‘sketched’ in 1.2. Following Mol (2008, p.95), and in line with the IE approach, I have not used the notion of ‘care’ as a fixed, theoretical concept, but as a “place to start” when thinking about what is important in the provision of healthcare services. This ‘logic of care’, Mol argues, involves “tinkering with bodies, technologies and knowledge” in order to work out “local solutions to specific problems” (Mol, 2008, p.14; Mol et al., 2010, pp.13–14), and as a *collaboration* between HCP and patient which “seeks to improve life” (2010, p.15).

As I close this chapter, I note that, even though Naomi feels hostility to the GP, she is still appealing for care. However, rather than empowering Naomi to make difficult change in diet or exercise habits, the preventive care practices she experiences cause Naomi to think that the “doctor doesn’t care”, to experience care as “fucking useless”, and describe the NHS as “No Swift Sunshine”. She sought help hoping for support, but comes back hopeless and isolated. This,

Chapter 5 Fitting lifestyle interventions into everyday life

according to Mol (2008, pp.97–98), is typical of patients who are “neglected” or “abandoned” — when “nobody is interested in their experiences with uncertainty, fear, shame, loneliness, and the never-ending pressure of having to take care of themselves”. In Chapters 5 and 6, I continue to explicate the problematic outlined here, by moving away from Naomi’s and others’ personal experiences, and examining the NHS Health Check programme, a major institutional initiative to prevent CVD. Through exploring the practices of HCPs delivering the checks, I extend what I have started to explicate in the social organisation of Naomi’s and others’ experiences.

Chapter 6 Getting checked out

In Chapter 5, I showed that authoritative forms of knowledge about prevention were at odds with Naomi's own understanding of her health needs. Naomi perceived these needs to be inextricably bound-up with her problems in everyday life and so she appealed for support to fit prevention work into this context. However, her attempts to have a conversation with her GP was reconfigured into snippets of lifestyle advice and into prescriptions for tablets. I presented the disjunctures in Naomi's (and others') accounts as instances when they were seeking 'care' — care which was flexible and adaptive and took their everyday concerns seriously. In this chapter, I start to explore why such appeals for care often go unheard within the institutional structures of preventive care. In order to explicate this problematic, I move the spotlight away from patients' health work, and their appeals for support to fit preventive work into their lives, to explore *HCPs' work* within health centres.

Health Checks have become the mainstay of prevention work (see Chapter 4) and aim to provide a "sophisticated" and thorough assessment of a patient's health, and support to prevent future disease (NHS Choices, 2016a). In theory then, a Health Check would help someone like Naomi to address issues relating to their life and body before these issues become observable health problems (such as, in Naomi's case, the obesity and hypertension, which are both contributing to her future risk of CVD, and also to current symptoms of gout, cellulitis and depression). I will not discuss Naomi's situation further in this chapter, suffice to alert readers that she is no longer eligible for the programme, following her diagnosis of hypertension. (As the Health Check is a "risk identification, communication and management programme" (Public Health England, 2013b), those already diagnosed with a risk condition are ineligible for the programme and managed separately (Public Health England, 2016e).¹⁰⁸) Naomi's health needs are being addressed within the routine care of the health centre. For the purpose of this analysis, the Health Check provides a window into

¹⁰⁸ Eligibility for different programmes of care opens up another set of ruling relations which are not explored in detail here.

both local and trans-local prevention work, setting the scene for the analytical threads into the work and the texts that are explicated in more detail in Chapters 6 and 7.

In this chapter, I base my analysis on an account of a patient's main Health Check appointment. I follow the patient pathway through the check, drawing on observations and interviews with HCPs in order to show the Health Check as a coherent, standardised, textual sequence with a general form that is replicated across every Health Check encounter. In Chapter 7, I move to Part 2 showing how information from this main appointment is processed, and how this is followed up with the patient. My aim is to show what *actually happens* in contrast to ideological understandings of the check (see 3.2) and, in particular, how HCPs' work is organised in ways which have consequences for both patients' own attention to their own lives and bodies, and to their relationship with the health centre. Attention to this work reveals troubling aspects that contradict the impression of the Health Check as routine and unproblematic.

As highlighted previously, the Health Check programme sits among a range of programmes across the health and care system which are designed to support people to 'live well' (Department of Health, 2013c). It claims to "spotlight behavioural risk factors" (Kearney, 2016a) and provide "individually tailored advice that will help motivate [patients] and support the necessary lifestyle changes to help them manage their risk" (Public Health England, 2016e). In this chapter, I show how this textually-organised 'lifestyle support' is triggered and delivered at particular points in the Health Check textual sequence. Some of the same textual processes appear in this chapter as in Chapter 5 (for instance the provision of 'lifestyle advice'). However, whereas in Chapter 5 I provided accounts of Naomi's (and others') experiences of lifestyle interventions, here I show them through observations of clinical encounters. I particularly highlight *HCPs' work* to deliver the checks, showing that, although help with lifestyle change is ideologically central it, *meaningful support* takes a back-seat to other more dominant institutional processes. I show how HCPs are drawn into textually-mediated 'ideological practices' (3.2) — allowing them to know their own work as offering "individually tailored" lifestyle support (Public Health England, 2016e), whilst often actively circumventing discussion of lifestyle issues. Before

proceeding to a primary analysis of the Health Check in practice, I start with a brief analysis of the structure and format of the Health Check in official policy representations.

6.1 Structure of the Health Check

As described in 2.6, the Health Check programme is commissioned separately from general medical services although, in English-region, the checks have been contracted to health centres. The Health Check comprises three main elements, as identified in Best Practice Guidance (Public Health England, 2016e): risk assessment; risk communication (or awareness); and risk management. The patient’s temporal progression through these elements runs left to right in the diagrammatic representation at Figure 20.

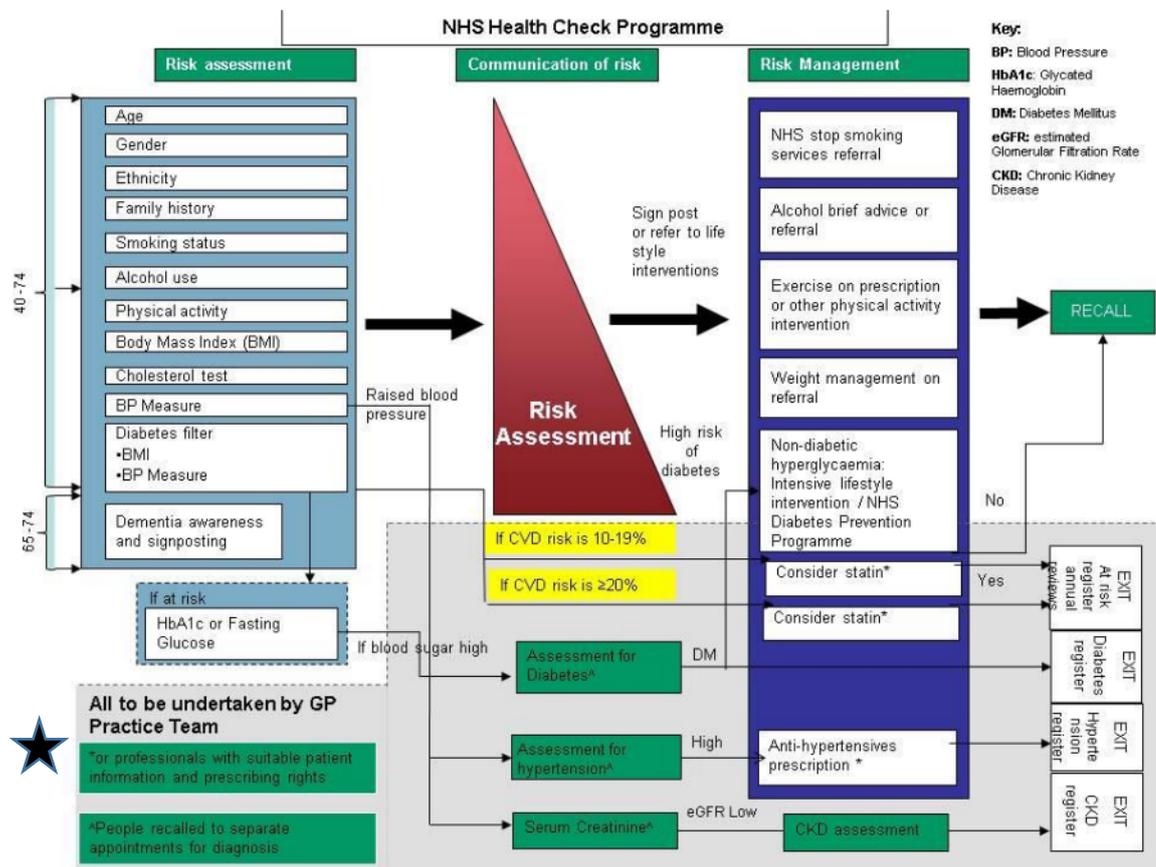


Figure 20: Overview of the cardiovascular risk assessment and management programme (from Public Health England, 2016e)

It is clear from this representation that the Health Check brings together multiple textual processes. For each shape or arrow shown in the diagram, a raft of clinical, and other, guidelines govern an HCP’s work. The individual work

processes involved may be carried out independently of the Health Check (during routine care) but, put together in this connected and systematic process, they form a coherent, standardised, textual sequence. First, various tests are carried out and information collected from the patient (the ‘risk assessment’ column), then a formal risk score is calculated (the big red triangle in the centre of the diagram under the ‘risk communication’ column), and finally a form of ‘management’ is undertaken such as advice given, or the patient referred to, or prescribed, an appropriate intervention (the ‘risk management’ column).

Although the Health Check is a single textual process, it is not (contrary to popular representations) a single appointment but is divided into two distinct ‘parts’ — ‘Part 1’ and ‘Part 2’ — based on the competences required for the work processes involved in each appointment. Although this may at first appear as irrelevant technical detail, I will show the division into two parts of the check to be integral to its delivery blueprint. In Figure 20, the two parts are illustrated by the white and grey backgrounds (white background corresponding to Part 1 of the check; grey background to Part 2). The caption ‘to be undertaken by GP Practice Team’, which relates to Part 2, denotes activities which must be carried out by “professionals with suitable patient information and prescribing rights” (see the star shape on Figure 20 which I have added to indicate this text). Part 1 activities (on the white background) by implication do not require these rights (competences). My observations demonstrated that, in accordance with the blueprint, a patient is only referred to Part 2 if they are identified with a physiological risk condition or are calculated to have a high risk score, for which prescribing expertise may be required, in contrast to the activities in Part 1. As one HCP corroborated, “the healthcare assistants can’t diagnose or prescribe, so that’s why [patients] go on to Part 2”. Most local delivery models (as in this study) follow the national blueprint, the first part being undertaken by a healthcare assistant and the second, if indicated, by a suitably qualified HCP (usually a practice nurse or GP).

6.1.1 Economic modelling

The division of the Health Check into two parts is partly practical (blood test results are not available immediately), but also builds on economic modelling of cost-effectiveness (Department of Health, 2008a; Drummond et al., 2015) — see

also 2.6. The calculations embedded in the modelling include several underpinning premises which are particularly pertinent to the discussion of the Health Check in this chapter.

The first premise is that the checks are delivered at low cost, utilising healthcare assistants and practice nurses at hourly rates of £22/hr and £28/hr respectively (for comparison, a GP hourly rate was costed in the same model at £138/hr). The professionally unregistered healthcare assistant role in particular increases the calculated cost-effectiveness of the checks as it commands relatively low rates of pay due to having “no set entry requirements” (Health Education England, 2017a). The Health Check economic model relies on this economically-focused stratification of HCP roles, organised to require only a limited set of competences for the initial assessment (Part 1), which can be easily gained with clinic-based or modular training (Public Health England, 2015c). With a minimal allowance for the costs associated with new diagnoses of risk conditions, the cost of delivering the checks was modelled at just £23.70 per check. As I will show, this structuring influences what is included (and excluded) in the templates for the different parts of the check (see below).

The second premise is that a standardised concept of risk (and risk reduction) is employed using risk calculation technology (QRISK2 — see 4.3.1) in order to generate an individual’s ‘absolute risk’ based on key risk factor data. This is very important in the modelling as it enables the benefits of different interventions to be quantified. In addition, it also provides a way for those at greatest calculated risk to be prioritised (thus improving calculations of cost-effectiveness). As the QRISK digital algorithm does not *directly* enter into Part 1 appointment, I do not discuss it in any detail in this chapter but instead highlight its role in Chapter 7.

The third premise I want to highlight here is that the subsequent interventions highlighted in the ‘risk management’ column of Figure 20 have been proven to be effective at reducing risk at reasonable cost. All the interventions in the model are supported by an evidence base, but this evidence base is limited to the interventions which have been funded for research, and proved to be effective. Pharmaceutical interventions, and those with easily modelled ‘outcomes’ are preferred within this frame (see 2.6).

These premises have framed the national and local development of the Health Checks programme, determining (as shown later in this chapter) the structure of the check, the interventions available, and the manner in which the check is delivered.

6.1.2 From economic model to the frontline: local templates and contracts

In order to make the Health Check actionable at the frontline, electronic Health Check templates have been produced and are adapted to regional requirements. In both English-town and English-county, two templates mirror the two parts of the check — incorporating all the requirements for the check into a ‘tick-box’ format.¹⁰⁹ In English-town, the service specification for the contract was collaboratively put together between GP leaders, the Clinical Commissioning Group and the local authority to ‘make it work’ — in other words to incentivise health centres to ensure that Part 2 is carried out where clinically indicated (see EX43, Chapter 8). They have achieved this by splitting the modelled payment¹¹⁰ into two parts, to align with the two parts of the check (described as Part 1: Risk Assessment and Part 2: Management Plan).¹¹¹ Additionally they have modified the consultation lengths from 15 minutes to 30 minutes for Part 1, and allocated appointment slots of 10 minutes (rather than the modelled 15 minutes) as part of GPs’ routine care for Part 2. Although these modifications might at first seem to jeopardise the economic model (e.g. utilising GP, rather than practice nurse time), this approach works for health centres, in part because keeping the checks in-

¹⁰⁹ Such electronic templates are integral to the efficient management of health centres’ frontline work through standardised appointment types for different categories of appointment, which specify particular work tasks (indicated by fields on the template) and appointment lengths. As one HCP contended “there is a template for everything”.

¹¹⁰ Although the economic model was never directly referenced by local policymaker informants, it was clear that modelling for the checks formed the basis of national policy and that this had travelled into local commissioning. Overall payment per Health Check in English-town and English-county local authority contracts was only very slightly inflated from the £23.70 modelled cost in the economic model.

¹¹¹ Note that, in English-region, the payment for Part 2 is not for ‘feedback’ (the second stage of the check as formulated in the economic model) but for a ‘management plan’ following diagnosis of a condition (i.e. the payments are designed to reimburse health centres for the costs associated with patients who are found to be at ‘high-risk’ of CVD, or are diagnosed with a risk condition).

house is considered to have practical benefits as well as the financial income it generates.¹¹²

Although the Health Check is delivered separately to routine care, health centres sometimes use the Health Check to support their routine work. For instance, I observed that HCPs sometimes refer patients for a Health Check when they face unexplained symptoms and when blood tests are indicated; the tests and lifestyle questions provide a basis for further consultation. By referring for a Health Check appointment, HCPs are therefore able to free-up time in the routine consultation, contain ‘sensitive’ and potentially time-consuming discussion about lifestyle within the Health Check appointment, and also ‘kill two birds with one stone’ by triggering a payment for the Health Check.

6.2 Looking for care in the face of everyday troubles: Mrs Green’s Health Check

In sections 6.1.2, I outlined some of the key features and organisation of the Health Check, with its many embedded textual technologies for assessing and managing risk. In the remainder of this chapter, I turn my attention to how HCPs work with this textual sequence and, in particular, how this prompts them to provide people with support to make changes to their lives and bodies in support of better long-term health. What follows is an account of my observation of Mrs Green’s Health Check (Part 1, the main component of the check (6.1)), delivered by Christina (healthcare assistant).^{113,114} In the subsequent analysis, I consider

¹¹² There are various explanations for this practical benefit. My data suggest that some health centres are concerned that, if they do not deliver the check ‘in-house’, they will have no control over the flow of referrals from an alternative provider of Part 1. I observed that HCPs also utilise the Health Check appointment to support routine care. The cost of doubling the length of the Part 1 appointment does not have a major impact on costs (when delivered by an HCA).

¹¹³ Most Health Checks were conducted by healthcare assistants – see 6.1.1. However, I observed that the standardised nature of the checks ensured that even when a medically qualified HCP delivered the Health Check (Part 1), the process looked similar — and similar problems and tensions applied. (In this chapter, I draw on observations of both HCAs and a GP who conducted Part 1 Health Check appointments. This GP delivered a few Health Checks as part of her oversight of the programme.)

¹¹⁴ In this excerpt, Christina mentions that the patient had been booked in for a ‘Well Person Check’, which many health centres provided prior to the inception of the Health Check programme, and continue to provide as part of their core services to people who are ineligible for the Health Check. These are no longer a prominent focus of health centres’ services.

the work of the healthcare assistant delivering the check and how this intersects with the everyday life and work of the patient who comes to be checked out.

In-between patients, Christina tells me about a 'brilliant' training course that she went on yesterday but we are interrupted as her computer screen indicates that Mrs Green has arrived. She tells me hastily that she had been hoping to show me a 'Well Person Check' and to try out some of the communication skills she had learnt on training. But the receptionist has booked this appointment incorrectly on the system — it is actually a Health Check, which has "a lot of fields to complete" (more than the Well Person Check), so there won't be time for trying out new techniques.

Christina goes to collect Mrs Green from the waiting room. They enter the consulting room, Christina introduces me, confirms that Mrs Green is happy with my presence, and asks Mrs Green how she is doing while she unwraps herself from coat, scarf and gloves. She is flustered, having rushed to get to the appointment, and having come straight from visiting her mother who has recently come out of hospital. She thinks she had "better get checked out" herself "with everything that's going on". She tells Christina about some problems with her mother (her mother's medication was stopped suddenly whilst she was in hospital, and triggered trigeminal neuralgia). Mrs Green talks briefly about how dreadful her mother's symptoms have been and points out to Christina that there is good reason why this condition has been described as 'suicide disease'. She has spent the last few weeks dealing with the practicalities of her mother's return home from hospital, visiting, arranging private care for her, as well as going to work and looking after her grandchildren.

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Christina acknowledges, asks some clarification questions, sympathises and then gets down to the business of the appointment. "So the first bit is really a box-ticking exercise," she says, turning to the screen. Completing the fields on the computer as she goes, she asks Mrs Green a series of questions, which elicit the briefest of answers.

"Can I call you white? ... Thank you." "Any family history of heart issues? ... Diabetes? ... Stroke?" "Do you smoke?" "Did you ever smoke?" "Do you drink?" "How much would you say?" "Do you know your height? ... Aha ... Weight?"

Mrs Green groans. Christina asks her to step on the scales. "It'll be too much" she says. Christina laughs and whips the scales out from under the couch and then pushes them back without indicating the measurement.

Christina: Do you have a chance to do any exercise at all?

Mrs Green: No, not really. (Pause) Not if you don't count up and downstairs all the time with the grandkids (gestures to indicate rushing around).

Christina: A bit of walking maybe? (Sounding hopeful)

Mrs Green: I work in town so I'm usually out walking round the shops for an hour at lunchtime.

Christina: Oh, that's good then – that counts (checking a box on the computer screen again to indicate that she does some exercise). What about your diet? – Good, average, poor?

Mrs Green: [Shrugging shoulders] It's OK.

Christina says that so long as she is trying to have her five portions of fruit and veg per day, and not eating "too much fat", that should be OK. Mrs Green acquiesces without commenting.

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Christina: Is it OK if I take your blood pressure? I might need to do it a few times.

Christina is cheerful and has a sympathetic tone. She measures Mrs Green's blood pressure, talking calmly to her as she prepares the cuff. We sit in silence as the machine does its work. After the first reading, Christina indicates that she'd like to do another one in a minute, but doesn't say what the reading is. 'I'll let you off' today, she repeats several times as she checks the machine and exchanges pleasantries — clearly recognising that the problems about which Mrs Green has just spoken may be causing a higher blood pressure measurement than she will be happy with. She takes another reading. 'That's OK' she says. Turning from the blood pressure machine to Mrs Green, she tells her, "Based on your blood pressure at the moment, we're going to do blood tests for..." She reels off some conditions (e.g. cholesterol, diabetes) for which her blood will be tested.⁷

Christina prepares to take a blood sample, getting the blood bottles and syringe ready. Mrs Green gets her arm ready by removing another layer. Christina reaches for a pillow from the couch and gently rests Mrs Green's arm on it. Mrs Green turns her head and closes her eyes. 'Are you OK?' says Christina. After several assurances from Mrs Green, still with her eyes closed, Christina turns her attention back to her arm 'You've got a good vein here'. There is a long pause as Christina inserts the syringe and fiddles with it – the blood isn't coming. 'Oh, you DID have [a good vein], but it doesn't seem to want to give me anything now!'

After a couple of attempts, when the blood finally flows and is bottled up and labelled, Christina asks to have a look at Mrs Green's 'water sample'. She does the dip-stick test at the sink – 'it's fine'. I understand her to be checking for blood sugars.

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As Christina returns to the desk from the sink, she returns to the subject of Mrs Green's blood pressure. 'Your blood pressure's not ideal so we've got two options – you could have a blood pressure monitor at home, or we could check it again here in a few weeks. It might just be down to your circumstances at the moment.' Mrs Green opts to come back in a few weeks' time and reads the cue that she should start replacing her warm layers. Christina indicates that the check is done and tells Mrs Green to call the receptionist in a week or so for the results of the blood tests. If the cholesterol is 'high', she should book to see the doctor – if it is 'OK', then she should rebook with Christina for a repeat blood pressure check. We say goodbye.

EX18: Observation of Mrs Green's Health Check appointment [from fieldnotes, February 2016]

Mrs Green, like so many other patients, brings many everyday troubles to the Health Check appointment. She tells Christina about a number of stressors which (as with Naomi in Chapter 5) are likely to be affecting her ability to address her diet and exercise habits — her weight, she says is “too much”. However, whereas many of Naomi's problems are directly related to material deprivation (and experiences which are characteristic of a deprived community), Mrs Green's troubles cross socioeconomic categories — e.g. her informal family caring work, and the general challenges of incorporating exercise and diet in an everyday life which is primarily sedentary, and laden with all kinds of stressors. As I explicate the problematic of this study (and the entwined disjunctures which are part of the social organisation of CVD prevention) (see 5.8), it is worth commenting that the kinds of troubles discussed here (and the difficulties in fitting preventive work into life) are not just experienced by the particularly socially deprived (an exception to a more usual rule), but also by those who would be considered to have very ordinary everyday lives.

Mrs Green's everyday life is important to the account I present in this chapter, appearing first when we discover that she has responded to an invitation to attend the Health Check because she thinks she “had better get checked out, with everything that's going on”. Although I was unable to discuss her reasons for attendance with her, she clearly recognises here that her everyday life (e.g. her caring responsibilities for her mother and her grandchildren) is impacting on her,

and she wants to check that it is not having any observable physiological impact. This fits with one HCP's explanation of why people attend the Health Check, as "they want to know they are healthy"; she presumes that the Health Check will reveal whether her body is functioning properly in the face of her everyday life vulnerabilities. It is reasonable to assume that this is how she has read promotional materials for the Health Check in which it is presented as a general 'check-up' much like a routine mechanical check on a car (an M.O.T.) (NHS Choices, 2016b).

However, although it is (superficially) obvious that Mrs Green attends because she wants to discover whether she is 'healthy', I understand, from observing her appointment and from discussions with other standpoint informants, that she, like Naomi (Chapter 5) looks for, and expects, a *conversation* with Christina about her health. Her everyday stresses understandably appear, from her standpoint, to be central to her overall health, and therefore to her Health Check appointment, and she brings these to Christina's attention; her understanding also appears to be backed up by Health Check promotional materials which inform patients that the check will provide a "sophisticated" check of "overall health", and "individually tailored support" (NHS Choices, 2016b, 2016a; NICE, 2014e). When Mrs Green talks to Christina about her family issues then, she is not just downloading her morning's misery to whoever will listen, but bringing them to Christina's attention as relevant information — relevant to the Health Check, and to her reasons for "getting checked out". Crucially, she does not only understand these issues as 'environmental factors' or as 'distal determinants of health' (see 2.1), operating only as background information to issues such as her weight, but as directly (and independently) involved in her health and wellbeing. Like Naomi, her stresses relate to her immediate experience of health *now*, rather than to an abstracted risk of *future* illness, and she wants to discuss them as part of a review of her health.

I noticed that many patients, like Mrs Green, brought concerns to their appointment which fell outside the Health Check's textual remit. This was particularly noticeable in checks carried out by a GP, as patients sometimes took the opportunity to ask for advice about current, symptomatic health problems. Dr Abel expressed considerable frustration at the end of one string of Health Checks,

telling me: “these appointments are for the Health Check only. If patients want to talk to me about chest infections, pubic boils, ear infections, hernias, addiction ... they need to book a separate appointment”. All of the issues Dr Abel mentions here had arisen within a handful of Health Checks. She had tried to deal quickly and efficiently with the issues with which these patients had presented, but this had meant that she had been working against the clock during each appointment and was, as a result, running 20 minutes late. In Mrs Green’s Health Check too, we see Christina working to complete the check within an allotted time. As she says, there are “a lot of fields to complete” and this is determined by the template (6.1). In contrast to a routine consultation which starts with a patient’s presenting concern, the Health Check template here determines what is discussed and what tests are carried out. This highly structured format chafes with the way patients may activate authoritative representations of the check as being about their “overall health” — which, to them is likely to include their own immediate health concerns. HCPs, as Dr Abel, often found themselves working between alternative knowledges — between a knowledge of the Health Check (and other prevention work) as based on specified, named, protocol-driven activity to be delivered at a particular time in a particular way, and patients’ knowledge of their everyday lives and bodies, and their understanding of their prevention needs as being an extension of routine, problem-driven medical care (see 6.4 below).

Both HCPs and patients may experience this tension. Christina commented to me that people often wanted “a bit of laying on of hands”, explaining that many of her patients look for encouragement, reassurance or motivation from her (especially in the Health Checks). In line with the analysis in Chapter 5, I understand this “laying on of hands” to represent a desire for an encounter which incorporates care practices which are flexible and adaptive to individual needs and which will help patients fit preventive work into their lives. Mrs Green, for instance, appears initially to look to Christina for some of this support but then, as Christina redirects her towards the Health Check template, to recognise that this will not be within the scope of the appointment; she responds to Christina’s cues by keeping quiet about her everyday life as she answers the template’s questions.

Although Christina is sympathetic to her patients, she also incorporates ruling understandings into her knowledge of her patients' care, considering their desire for a practical conversation to be a distraction from her more pressing work. She, and other HCPs, explained to me that these people are characteristically '*healthy*' but *unnecessarily anxious*. In other words, she predicts that they will not be shown (using authoritative categories) to have anything biomedically wrong with them, and she therefore sees their everyday (health-related) troubles as irrelevant. (This group of patients were frequently described as the "worried well" — see 4.3.2). As Christina activates this understanding, she reframes her knowledge of her patients, describing them as 'worried' or 'anxious' which, although a description rooted in reality, becomes double-sided (see 2.3.1) — having an alternative meaning implying that they were causing problems for the smooth-running of the health centre's work. When Christina listens sympathetically to Mrs Green, she understands this part of the appointment to be just 'small talk' prior to completing the standardised Health Check template. She listens, but her focus is on initiating the Health Check sequence. She asks no questions about how these issues are affecting Mrs Green's health, and participates in no discussion of the issues Mrs Green has raised. In the following section, I show instead how she defers to the Health Check template's lifestyle questions, which she uses to capture a textual representation of Mrs Green's everyday life. I highlight Christina's work to textually represent Mrs Green's everyday life as 'lifestyle', how this *excludes* her everyday life, and how this minimised representation of lifestyle is then used as the basis for different forms of potential action.

6.3 Providing "individually tailored advice"

Mrs Green's situation is obviously unique, yet it also typifies (as in Naomi's case) the inseparability of people's everyday lives from what are described in CVD prevention policy as 'lifestyle' or 'behavioural' risk factors such as diet, exercise, weight or smoking habits. Policy separates these lifestyle factors out of the messiness of everyday life by virtue of their tractability (being 'modifiable' or 'avoidable' — see 2.4). According to the CVD Outcomes Strategy (Department of Health, 2013a), lifestyle factors "reflect an individual's circumstances and choices" and therefore "can be changed for the better". The more messy,

complicated, social parts of everyday life however are not included as directly modifiable, described instead as ‘social and environmental’ risk factors (Public Health England, 2016a) which fall largely outside of the remit of healthcare provision such as the Health Check. Although their importance is recognised in broader policy (Public Health England, 2014a), they are not considered to be directly relevant to individual healthcare programmes such as the Health Check (see 2.7). However, Mrs Green’s Health Check serves as a reminder of the connection between everyday life and lifestyle risks, which are consequently much more difficult to modify in practice than policy suggests. In this section, I highlight that the practices which HCPs understand to be providing “individually tailored advice” (Public Health England, 2016e) which will take account of their individual risks.

The Health Check template (6.1.2) incorporates a set of questions for the patient about their lifestyle. These questions contribute to the extensive number of fields to be completed within the 30-minute appointment. Christina knows that she needs to move quickly through the template, because (as she indicated to me at the start) there are “a lot of fields to complete” (EX18). Her comments tie up with Lena’s (another healthcare assistant) when I first approached her about observing Health Check appointments. Lena had questioned why I would be interested: “I don’t know how much help it will be to you” she had said apologetically, adding “I can only ask the questions really”. Like Christina, who describes her healthcare assistant role as “information gathering”, she considers the Health Check to be a simple and routine type of appointment, involving asking questions and entering the answers into the template. In line with this knowledge (about the competencies required, and the allocated appointment time), Christina draws Mrs Green into the cost-effective delivery of the programme with her prompt that “the first bit is really a box-ticking exercise” — thus communicating to Mrs Green that the questions should not precipitate lengthy answers. The template’s sequence of questions then textually organises which information is considered institutionally useful, and which, by omission, is not required. Christina asks Mrs Green questions relating to: tobacco smoking; alcohol (“drinking”); body mass index (BMI) (from measures of weight and height); exercise; and diet. As discussed in 6.1.1, these specific lifestyle factors were

included in economic modelling (and on the template) as they are considered to be amenable to modification, utilising interventions which are cost-effective, with a proven evidence-base. Other factors, such as stress, however are not included, because they are not considered to be “direct proximal causes of disease” — they are “further back in the causal chain and act via a number of intermediary causes” (World Health Organisation, 2010a).¹¹⁵ This constrains the categories embedded in the Health Check template; Christina is organised not to consider the stresses of Mrs Green’s everyday life to be relevant, even though they are the ‘direct, proximal causes’ of her *concerns* about her health.

Most of the communication between Christina and Mrs Green is related to how Mrs Green’s life and body should be *represented* in the template; other information and conversation appears to be extraneous. We see this when Christina asks Mrs Green about her exercise and they have a brief discussion about what ‘counts’ for the purpose of the template. She then asks Mrs Green to fit her diet into one of three categories — “good, average, poor?”¹¹⁶ It is not clear quite what Mrs Green’s shrug indicates — perhaps that her diet is not ideal, or that she is not sure how to evaluate and categorise it. In any case, Christina appears to have little interest in the answer, just telling her that it “should be OK” so long as she eats five portions of fruit and vegetables per day and refrains from “too much fat”. From Christina’s perspective lifestyle questions allow HCPs to quickly identify “red flags” — answers which (textually) point to the need for intervention. As she works through the questions on the template, it is clear that she is applying her knowledge of clinical guidelines in relation to each of Mrs Green’s lifestyle answers, and determining whether Mrs Green’s answers are ‘OK’ — or not. This screening process allows HCPs to direct patients to “focus on the things that they could change” (interview with Lydia) — to identify aspects of

¹¹⁵ Links between ‘psychosocial stress’ and CVD are long-established (e.g. Rozanski et al., 1999), but, as the factors involved are complex and interrelated, it is difficult to demonstrate the effectiveness of interventions to address them.

¹¹⁶ It is instructive here that Christina creates her own categories of “good, average or poor” which are not required by the template (she is only required to tick a box to say that she has asked about lifestyle). This seems to help her to elicit a speedy response from Mrs Green, which will allow her to ‘give advice’ whilst not requiring discussion.

their lifestyle which do not conform to institutionally authorised standards, and highlight how their behaviour could be corrected.

Another example is illustrative. In one of Dr Abel's Health Check appointments, she discovered that her patient was drinking several pints of beer every evening. I observed her getting out an alcohol calculator, carefully checking the alcohol content of his preferred drink, calculating his weekly number of units, and plugged the information into the computer. When she had finished the set of lifestyle questions, she announced, "you need to cut down on your alcohol, you're drinking double the limit". The man agreed and Dr Abel moved onto taking blood. Although in the above example, the patient mentions various aspects of his everyday life which are likely to be contributing to his drinking, there is no discussion of how he might go about addressing the issue, or integrating a change into his life. Neither is there any discussion of the reason for, or benefits of, doing so. Dr Abel simply compares him to the authorised standard and ensures that he knows what action he should take to realign himself with this standard. Similarly, in Mrs Green's Health Check, what might be understood to the patient as 'conversation' is removed from the interaction; Christina goes directly from collecting information, to evaluating Mrs Green's compliance in a way which looks more like an audit than a clinical consultation.

Each time that Christina asks a lifestyle question, she ticks a box on the computer screen, to indicate on the template that she has asked the question and 'given advice'. Using IE's theoretical approach to understanding the role of texts (3.2), Christina's action is a good example of (part of) a work-text-work sequence. Christina works with Mrs Green to provide a succinct representation of her lifestyle. She then screens these answers using ruling categories which allow her to textually identify whether the answer is, or is not, a cause for concern. Christina then is able to provide lifestyle 'advice' which is, from inside the ruling relations, 'tailored' to the individual, insofar as it relates to the specific lifestyle information provided by the patient. It should be noted that both Christina and Mrs Green are working here. Mrs Green is submitting to scrutiny whilst keeping quiet about other aspects of her everyday life (as Naomi does when she 'sits there' and is given a diet sheet when she 'opens her mouth' (EX5)). This requires mental work relating to what of, and how to present, her everyday life to fit the template's questions.

Christina on the other hand works to help Mrs Green reformulate her everyday life into categories which allow her to enter the information into the template and to 'give advice' as textually indicated. This 'advice' is organised to be integrated with information gathering; Christina ticks the boxes to say she has given advice as she works through the template.

When Christina provides lifestyle advice, she uses standardised recommendations relating to specific lifestyle factors; it is part of her role to remember these. For instance, she knows that the current NICE recommendation is for all adults to be "active daily" and that this should add up to "at least 150 minutes of moderate-intensity physical activity" over the course of a week (NICE, 2013) — see 4.1. When Mrs Green reveals that she walks around the shops in her lunch break, Christina's exclamation "that counts" indicates her relief that she will not need to advise on exercise; Mrs Green is satisfying the textual requirements for physical activity and she can move on with the next question. However, when Mrs Green fails to reassure her however that she is eating a 'healthy diet', Christina provides some standardised, verbal dietary advice, based on widely-promoted recommendations such as the Eatwell Guide and Five-A-Day (Public Health England, 2016f; NHS Choices, 2017) (4.1). In this appointment, although Christina expects that Mrs Green knows the information already¹¹⁷, she dispenses lifestyle advice in the form of a brief (one-way) injunction, abstracted from any inquiry about larger issues related to Mrs Green's diet such as access to shopping, food budget, or the specific demands on Mrs Green's time and energy as they relate to her work to be healthy. Although her work is ideologically understood in policy to be making the patient aware of their risk ('risk communication' in Figure 20) as a catalyst for people to change their behaviour, the institutional knowledge embedded in it chafes with Mrs Green's existing concerns about her lifestyle risk— which she knows to be more complex and interrelated than is recognised within the Health Check's template.

It is important to note that Christina is not demonstrating any lack of professionalism or competence here. According to ideological representations of

¹¹⁷ HCPs often told me that patients "*know*" in a semi-despairing manner.

her work, she is providing “individually tailored advice that will help motivate [patients] and support the necessary lifestyle changes to help them manage their risk” (Public Health England, 2016e). However, the time constraints of the template and the textual architecture for capturing lifestyle information, and then imparting lifestyle advice, inhibit any more detailed discussion of lifestyle issues, and almost entirely exclude the everyday life lying behind them.

6.4 “Are you alright with needles?”: the trouble with life and lifestyle

Although HCPs are keen in principle to be involved in raising and discussing issues around lifestyle (they understand the importance of people’s care for their bodies to their health), in practice doing so creates tensions because of the sensitivity of these issues. HCPs are therefore reluctant to raise them in routine care unless precipitated by a computer prompt, or unless the patient’s presenting symptoms indicated a particularly conspicuous lifestyle problem.¹¹⁸ The Health Check template (with its embedded lifestyle questions) forces them to broach issues which, without its structure, run the risk of appearing rude or insensitive (interview with Dr Abel).

However, even within the Health Check appointments, however, lifestyle questions do not lose all of their awkwardness. As one healthcare assistant describes it below (and as indicated by Naomi in Chapter 5), patients are often fearful of ‘getting told off’, and this affects their relationship with their HCP. HCPs told me that they empathised with their patients, recognising that many of them face significant issues in their everyday lives which are not easy to change, and which impact on these lifestyle behaviours. They understand this, at least to some extent, from their own, personal experiences:

¹¹⁸ Examples include patients presenting to the GP with respiratory problems (which may precipitate a question about smoking) or joint-pain (which may lead smoothly to a discussion of their weight).

I think it's very hard when it comes to alcohol, diet and exercise, and I'm sitting here telling the patient, I think I've done none of those for two days, so, you know, I do say to them 'I'm not here to preach, and 'I do understand, because I haven't done it for two days [either], don't worry'. I think sometimes they come in and think 'she's going to tell me off'. I'm not here to tell anybody, I'm just here to advise.

EX19: Lena

HCPs work to rationalise the social faux pas of asking lifestyle questions by pointing out that patients *expect* to be asked to disclose this type of information during the Health Check.¹¹⁹ However, as shown in EX19, they nevertheless try to mitigate the social awkwardness of the interaction in a number of ways. For example, Lena here reassures patients not to worry as she is ‘just like them’, bolstering the relationship with the patient by sympathising, and distancing herself from the lifestyle questions’ moral appraisal. In my observations, HCPs hid behind the Health Check template, apologising for it in order to demonstrate that these questions were standardised, rather than personal to them. For example, when Christina tells Mrs Green that “the first bit [about her demographic and lifestyle information] is a box-ticking exercise”, she is not only working to draw Mrs Green into the template, but is also actively positioning the template as the agent responsible for ‘asking the questions’. Christina disassociates herself from the offending questions, minimising her own role and depersonalising a potentially awkward interaction. In doing so however, she removes the possibility of an engaged discussion with the patient about the answers to these questions. Similarly, HCPs work to elicit unproblematic answers, encouraging best-case answers in particular to ill-defined questions about diet and exercise. For example, when Mrs Green confesses to Christina that she does not really do any exercise, Christina gently cajoles her to disclose her “bit of walking” around the shops in lunchbreaks, actively seeking to draw out more information which will not set in motion a requirement to provide advice (or to “preach” as Christina

¹¹⁹ There exists an extensive body of work looking at the interactional work between HCP and patient. Authors such as Pilnick et al. (2009) have recognised the institutional influences on this work.

characterises it). “That counts,” she says cheerily as she checks the box on the computer screen. In this way, HCPs work to coordinate everyday life into unproblematic categories. Sometimes however, this is not possible. An example from another Health Check (below) serves to illustrate this.

Mr Brown was in his late 40s. As he sat down, he asked “can you prescribe some antibiotics for my cough?” On further investigation Dr Abel discovered that he was bringing up “green mucus” and that he had started smoking again recently (having previously stopped for a while). As she then redirected him to follow the Health Check template, Mr Brown told Dr Abel that he had started smoking again “rolling on from everything else that’s going on”¹. As this could not be unproblematically entered into the template, she offered to refer him to support for smoking cessation if he was “ready”. He declined. Instead, he mentioned a hernia operation about which he was concerned (Dr Abel broke off from the template to check his abdomen) and that he had been “suffering from depression quite bad”. He said that he “was trying to get his mind back on track”, as part of support for amphetamine use and that he had cut down radically on his previously heavy alcohol consumption.

EX20: A fragment from my notes on Mr Brown’s Health Check [from fieldnotes, March 2016]

Clearly Mr Brown is struggling with his life and lifestyle. Theoretically then he is someone who the Health Check programme is designed to identify and support — as he is particularly vulnerable to CVD and other health problems in the future. In addition, commissioners of the Health Check programme put considerable efforts into ensuring that the programme reaches those who are understood to need it most — i.e. those, like Mr Brown, from deprived backgrounds. However, as in Christina’s consultation with Mrs Green, Dr Abel repeatedly pulled him back to the template with “there is a lot to cram in”. Her concern was with getting the appointment completed, and I sympathised with her need to do this. When Mr Brown told Dr Abel that he was having some support with his drug use, it was clear that, even in a 30 minute appointment, she could only scratch the surface of his health issues.

Nevertheless, the experience of observing this Health Check was unsettling. Mr Brown clearly found it uncomfortable, if not shameful, to answer the template's lifestyle questions — yet he had booked the Health Check appointment, presumably because he understood it as an opportunity to talk about his general (immediate) health concerns (6.2). However, when he started to try to talk to Dr Abel about his work in “trying to get back on track,” Dr Abel resolutely moved him on: “We are at the blood test part of the Health Check now” she pointed out, “Are you alright with needles?” Bearing in mind his previous revelations about his ongoing use of injectable drugs, this interaction was, at one level, grimly amusing; Mr Brown subtly rolled his eyes as I looked over to see his reaction. At another however, it was deeply troubling. Dr Abel appeared not to have registered him talking about his drug use, or realised that her question about whether he was ‘alright with needles’ seemed misplaced. More importantly, she had not acknowledged his story of working to get back on track or seen that, for him, this appointment was *part of* that work. Although a sympathetic doctor, who showed concern in our interviews for the difficulties of her patient population, in this interaction, she seemed disengaged and unconcerned. Although she made an effort to address his cough and check his abdomen, his underlying everyday life, and even his individual lifestyle behaviours (a stated focus of the Health Check programme), went largely unrecognised within the appointment.

The Health Check's model relies on referral to separate lifestyle interventions in order to support patients with more complex ‘lifestyle’ needs. Dr Abel offers to refer Mr Brown for support to stop smoking according to Health Check guidance (Public Health England, 2016e) (4.1). Such interventions are important to the smooth-running of HCPs' work, providing something to offer the patient with an intransigent lifestyle problem; however they are also another way in which lifestyle support is ‘organised out’ of the clinical consultation. HCPs report that they occasionally make referrals, but that patients often “can't be bothered” to attend. However, the *offer* of referral provides some kind of a ‘solution’ for Dr Abel in the context of the Health Check appointment, and (as the support is entirely contracted out to the independent provider). The patient's lifestyle and everyday life issues are removed from the domain of clinical consultation, and the responsibility for addressing his lifestyle issues shifts from a collaborative effort

between HCP and Mr Brown to a task for Mr Brown alone; he is understood to have declined support (to be ‘unbothered’ by his health) if he does not attend or complete the intervention.

6.5 What matters in the Health Check?

As I have shown throughout this chapter, the Health Check’s textual sequence (Part 1) with its multiple embedded textual technologies organises HCPs to systematically overlook patients’ everyday lives. Instead, they activate a suite of nested, textual processes under the banners of ‘lifestyle advice’ or ‘lifestyle interventions’ to correct aspects of patients’ lifestyles which are textually identified as being particularly risky. I showed in 6.3-6.4 that managing a patient’s lifestyle in this way allows HCPs to meet the pre-established requirements coordinated by the template and concurrently maintain strict boundaries around the issues which patients may discuss, ensuring that complicated, awkward, or ambiguous conversations are avoided and that the Health Check proceeds within the allocated time. Although lifestyle interventions by other providers should, in theory, offer more dedicated support for specific lifestyle needs, I showed in Chapter 5 that these are not widely taken-up, and that what happens at these interventions may be at odds with patients’ understandings of their needs (see 5.6). The Health Check therefore, although ideologically providing access to personalised support for lifestyle change, appears in practice to actively shape HCPs’ work to restrict this support.

What then is important within the Health Check’s textual sequence? What matters in Part 1 is the referral to Part 2 — to an appointment with an HCP who is able to “diagnose and prescribe” (Lydia). Although Christina had looks out for “red (lifestyle) flags” as she progresses through Part 1, it turns out that the primary purpose of the information gathered is to screen Mrs Green for referral to Part 2

(indicated by the shaded area in Figure 20).¹²⁰ Either the HCP completing the Part 1 template, or another HCP receiving blood test results, refers the patient if tests indicate that a risk condition may be diagnosed (e.g. hypertension, hypercholesterolaemia, diabetes).¹²¹ From an institutional perspective, abnormalities signal that the patient needs medical review in anticipation of medication to manage their condition. In Mrs Green's Health Check, the referral to Part 2 is indicated when Christina raises a concern over Mrs Green's blood pressure (requiring a retest) and tells her to "book to see the doctor" if the cholesterol result is "high". (Following clinical guidelines, she knows that these results are outside of normal range.)

Identifying people who are 'at risk' is not just a matter of screening for risk conditions however. As one HCP told me (and policy emphasises), "the whole idea of the Health Check is to calculate [the patient's] estimated [risk] score within the next 10 years" (4.3.1). This, I was told, is calculated by "pressing a button" from within either of the Health Check templates (interview with Dr Abel). However, although in Figure 20 it forms a primary textual and ideological basis for further action (risk scoring is represented by the big red triangle marked 'risk assessment'), and although it is a legal requirement of the Health Check (Public Health England, 2016e), I saw no reference to risk scoring during my observations of the main Health Check appointment — including my observation of Mrs Green's Health Check on which I have based this chapter. I related this anomaly to a disjuncture between institutional knowledge of risk scoring as motivating patients to change their lifestyle (and therefore it being important to communicate the risk score to patients), and HCPs' knowledge of having to explain risk to patients; HCPs delivering Part 1 (usually a healthcare assistant)

¹²⁰ I refer here to the common use of screening as work to "test or examine someone or something to discover if there is anything wrong with him, her, or it" (Cambridge English Dictionary 2017). Since the inception of the Health Check programme, there has been a debate about whether the programme should have been categorised as a 'screening' programme. A parliamentary review indicated that "anything that looks like a screening programme" (e.g. the Health Check programme) should in future be subject to the more stringent scrutiny required for such programmes. I do not enter this debate here, but note that, using common parlance, HCPs' work as shown in this chapter is 'screening work'. The term is also used in many academic papers.

¹²¹ Details of local health centre protocols vary but, at both Riverbank and Wildwood, a GP screened blood test results when they were returned to the health centre to determine whether a Part 2 was needed. This happened several days after the patient had attended the appointment.

were sometimes considered unable to explain risk scoring (Riverbank), or appeared to be lacking in confidence to do so in practice (Wildwood).¹²² In Chapter 7, I take up the disjuncture highlighted here, investigating the textual significance of the risk score, which had such central positioning in the Health Check textual sequence, but which appears illusive here.

6.6 Care ‘lite’: a disengaged version of care

In this chapter, I have shown that attention to HCPs’ work of delivering Health Check appointments reveals troubling aspects that contradict the impression of the Health Check as routine and unproblematic. Patients attend the Health Check for different reasons. In promotional materials it is an opportunity for a comprehensive check of overall health, and many attend hoping for a discussion and personal support with the difficult issues relating to their everyday lives and lifestyles — knowing that these affect their health. I have shown however that HCPs’ work is shaped in line with the Health Check template, and that as HCPs activate the template, they systematically inhibit meaningful discussion of life or lifestyle. (This is despite the fact that they may understand themselves to be providing individualised support through one-line injunctions or referral to an intervention.) The tensions created by the organisation of their work result in many HCPs actively *disengaging* with their patients’ presenting needs; they simply do not appear to have the time to fill in the gap between ideological versions of lifestyle support and what their patients appear to want from them. Instead, they characterise patients who want to talk to them as the “worried well” if they are not immediately identified with a lifestyle or physiological risk condition which warrants institutional attention. Evidence from conversations with patients

¹²² At Riverbank Health Centre, the formal risk score was only calculated by a GP after blood test results were returned from the lab and determined, along with the results of physiological tests, whether the patient was referred to Part 2. According to Christina, this was “doctory stuff” (requiring a different form of expertise to that of HCAs). At Wildwood Health Centre, on the other hand, HCPs told me that they carried out a preliminary risk assessment (prior to the return of blood tests) during the Part 1 consultation, but explained that a technical problem accounted for its absence during the period of my observations (by preventing them from accessing the risk calculator from the Part 1 template). In this scenario, a GP would recalculate the risk score when blood test results were available. I discovered from conversations with HCPs working in other health centres that it was commonplace to defer risk scoring until after the blood test results were returned (even though it was a statutory requirement of the checks that “the person having their NHS Health Check is told their cardiovascular risk score, and other results are communicated to them” (Public Health England 2016b)).

(Chapter 5) demonstrates that when HCPs distance themselves from their patients, patients may well also disengage from trying to generate constructive discussions about their health.

All the HCPs whom I observed delivering Health Checks demonstrated some interest in their patients' everyday lives and, to varying degrees, empathy with them; however, they simultaneously understood these aspects of care to be time-consuming and unproductive (not being required by the template), and worked to minimise superfluous talk (which was not contributing to its completion, but which could have presented valuable opportunities to discuss important aspects of patients' lifestyles). As a result, the relational aspects of their work appear 'more style than substance', characterised by sympathetic tones rather than active or meaningful engagement with either the answers to lifestyle questions or the everyday life underpinning them. In some regards, their approach may make the experience of attending the check easier (less challenging or judgemental) for the patient, but my data suggest that it primarily serves to avoid confrontational and/or time-consuming conversations, rather than being in patients' interests.

The role of healthcare services (particularly general practice) in 'promoting health' or 'preventing disease' has been the subject of much debate (Peckham et al., 2011). However, the Health Check programme is an example of the increasing emphasis on prevention. The programme, and risk management practices more generally, ideologically aspire to collaborative partnerships between patients and HCPs. This chapter however has shown that this partnership is undermined by the social organisation of the Health Check. Instead of providing support for people to fit prevention into their everyday lives, HCPs' work is organised according to the template's textual categories to screen patients quickly and efficiently for a textually-constructed notion of 'risk'. This is what matters institutionally, as I will examine in more detail in Chapter 7. The immediate, pressing stresses of everyday life which patients bring to preventive consultations have institutional relevance of course, but they are not what matters most.

Chapter 7 Acting on risk: knowing what to do

In this chapter, I continue mapping a patient's journey through the Health Check, picking up after completion of the Part 1 template (when an HCP calculates the risk score using a digital algorithm integrated into the Health Check electronic templates), and following the patient into the Part 2 consultation. I show how risk scoring technology utilises the information gathered in Part 1 to calculate an overall assessment of an individual patient's risk. I then show how HCPs intervene in the lives of patients who are shown to be at high risk, activating the risk score as a diagnostic category for which they recommend lipid lowering medications (usually statins) in accordance with clinical guidelines. The NICE guideline (CG181) recommends that HCPs offer patients statin medications, but it also contains recommendations about lifestyle change, and about how a decision about statin medications should be made — particularly emphasising that patients should be “involved” in the decision (NICE, 2014f). However, I show that HCPs' focus is organised by a textual link between the risk score and statins, and that this link shapes their other work relating to how they involve their patient in knowing and managing their risk.

Patients on the other hand bring alternative knowledge about their lives, their risk, and about medication to the Part 2 consultation (and to their encounters with HCPs more generally as I showed in Chapter 1). This is not only their private knowledge of their own individual circumstances and preferences, but also understandings (and sometimes confusion and uncertainty) from news media coverage of controversies around the evidence for statin medications. In this chapter, I highlight what happens when patients' and HCPs' knowledge come together at the point of deciding how to act on the risk score. HCPs generally understand their work to communicate the risk score as routine and unproblematic, emphasising that “following guidelines” is good clinical practice. In keeping with this approach, they work to break down, what they describe as their patients' “barriers” to statin medications. Although they describe the overall process as “shared decision-making” and “involving” patients, I show that these are ideological concepts — ‘shell terms’ which are filled with an authoritative management agenda (see 3.2). In using them, HCPs create an account of their work that does not necessarily reflect the embodied experience of patients. I

consider the tensions arising for patients when they are reluctant to agree to the treatment which HCPs are recommending.

I draw primarily on HCP interview-accounts of delivering Part 2 of the Health Check at Wildwood and Riverbank health centres, where I had also conducted observational fieldwork.¹²³ I focus on HCPs' work, but also show that their work in turn creates new challenges for patients — particularly those who are troubled at the idea of lifelong medications and who find themselves negotiating with HCPs or flouting their advice. I highlight *what actually happens*, highlighting tensions between institutional knowledge of risk management with statins and 'shared decisions', and patients' experiences of being confronted with a decision about whether or not to take them.

7.1 Knowing health as statistical probability about the future

First, I show how HCPs activate risk scoring technology, and then the risk score itself, as part of the Health Check textual sequence. In the following excerpt, Lydia (practice nurse) narrates an account of the next step of the Health Check's sequence, taking up where my observations had finished (Chapter 6).

Interviewer: So you've done the health check, you get to the end of Part1, and you do a risk assessment?

*Informant: So what we do is, you have your conversation about lifestyle (so smoking, diet, drinking, exercise, family history and any other medical issue that they've got) and then you put all those details in. **I** [emphasised] do [the risk score] when they are there, so then you've got a result, and you say 'this is your initial risk' and explain what that risk means, and then obviously wait for their cholesterol results to come back, and then redo the risk. [emphasis mine]*

EX21: Lydia

As outlined in 6.5, risk scoring is often omitted from Part 1 of the check (being carried out in the patient's absence when blood test results were returned), but

¹²³ I was unable to observe Part 2 consultations as these were interspersed with routine consultations; GPs sometimes telephoned patients to complete the Part 2 consultation.

Lydia emphasises to me that it is important to calculate it when the patient is present. Perhaps (I have a hunch) she differentiates her practice here because she is aware of the legal requirement to communicate the risk score to patients as part of the Health Check, and is aware that this may sometimes be omitted.¹²⁴ She tells me that the risk score collates information about the patient from Part 1, and turns it into a “result” — a single measure of risk for that individual patient. As I showed in Chapter 6, the “conversation about lifestyle” in Part 1 (to which Lydia refers here) was often, in practice, organised around completing the template as quickly and efficiently as possible, and involved little ‘conversational’ interaction. As Lydia progresses to “do the risk assessment” — the climax of the consultation — she sets aside the questions and answers of the Part 1 template (including any knowledge of her patient’s health needs gleaned during this process) in favour of knowing her patient through their risk score, which will then guide what she should do next. Even if, as in Mrs Green’s case, a risk score is not generated “while they are there” (i.e. during the appointment), the HCP conducting the Health Check knows the risk score as the main purpose of the Health Check (see 6.5). In addition to the discovery of abnormal physiological biomarkers, a high risk score also indicates that a patient should be referred for a Part 2 consultation (Figure 20).

In Figure 21, I illustrate how risk scoring technology generates a risk score from an individual patient’s data. Figure 21 is a snapshot of the QRISK2 online calculator (which uses the same algorithms as the QRISK2 calculator used in clinical practice), and into which I have entered estimated data for Mrs Green¹²⁵ (6.2) in order to calculate an approximate risk score. In clinical practice, HCPs calculated the risk score by “pressing a button” (interview with Lena) from within the Health Check template which linked to the risk scoring technology.

¹²⁴ Lydia is an experienced practice nurse, and well-attuned to best practice guidance. In EX21, she emphasises the “I” in “I do it when they are there”, highlighting that this may not be how all HCPs at the health centre practise (corroborated by my accounts in Chapter 6).

¹²⁵ I used Mrs Green’s age of 66, and an estimated BMI of 31 (Height 165cm: Weight 85kg). The online tool uses the same set of algorithms to that embedded in the health centre’s electronic systems (see footnote 6 below Appendix 1).

Chapter 7 Acting on risk: knowing what to do

This calculator is only valid if you do not already have a diagnosis of coronary heart disease (including angina or heart attack) or stroke/transient ischaemic attack.

Reset Information Publications About Copyright Contact Us Algorithm Software

About you

Age (25-84):

Sex: Male Female

Ethnicity:

UK postcode:

Postcode:

Clinical information

Smoking status:

Diabetes status:

Angina or heart attack in a 1st degree relative < 60?

Chronic kidney disease (stage 4 or 5)?

Atrial fibrillation?

On blood pressure treatment?

Rheumatoid arthritis?

Leave blank if unknown

Cholesterol/HDL ratio:

Systolic blood pressure (mmHg):

Body mass index

Height (cm):

Weight (kg):

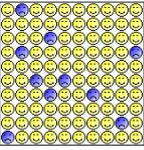
Calculate risk over years.

Your results

Your risk of having a heart attack or stroke within the next 10 years is:

10.1%

In other words, in a crowd of 100 people with the same risk factors as you, 10 are likely to have a heart attack or stroke within the next 10 years.



Risk of heart attack or stroke

Your score has been calculated using estimated data, as some information was left blank.

Your body mass index was calculated as 31.22 kg/m².

How does your 10-year score compare?

Your score	
Your 10-year QRISK [®] 2 score	10.1%
The score of a healthy person with the same age, sex, and ethnicity*	9.7%
Relative risk**	1
Your QRISK [®] Healthy Heart Age***	67

* This is the score of a healthy person of your age, sex and ethnic group, i.e. with no adverse clinical indicators and a cholesterol ratio of 4.0, systolic blood pressure of 125 and BMI of 25.
** Your relative risk is your risk divided by the healthy person's risk.
*** Your QRISK[®] Healthy Heart Age is the age at which a healthy person of your sex and ethnicity has your 10-year QRISK[®]2 score.

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Figure 21: A snapshot of the QRISK2 calculator (web-version) showing Mrs Green's "initial risk" (EX21), prior to blood pressure and cholesterol results

The QRISK2 (similar to other risk scoring technologies) generates a probability that an individual patient will have a cardiovascular event¹²⁶ over the following 10 years (Collins and Altman, 2012; Public Health England, 2016e, 2016c) (see 4.3.1). The Part 1 template provides the variables required for risk scoring: age; cholesterol ratio; systolic blood pressure; smoking status; body mass index; family history of coronary heart disease; Townsend deprivation score (from postcode data); treated hypertension; ethnicity; type 2 diabetes; rheumatoid arthritis; atrial fibrillation; and renal disease. These are well-established variables which are "known or thought to affect cardiovascular risk" (Hippisley-Cox et al., 2008), based on statistical findings relating to individual risk factors. 'Overall', 'total', or 'absolute' risk (the "result" to which Lydia refers) seeks to aggregate these factors for an individual patient. As highlighted in 4.3.1, the risk score is institutionally significant, since it enables policymakers to "**focus resources** on those at greatest risk, and hence with most to gain" (NICE, 2014f) (emphasis

¹²⁶ CVD includes myocardial infarction, angina, coronary heart disease, stroke, or transient ischaemic stroke. For simplicity, this is abbreviated to 'heart attack or stroke' in the text provided in Figure 21.

mine). As detailed previously, the ‘resources’ to which this guideline refers are lipid modification medications. The threshold at which the CG181 recommended that HCPs should offer medications had been lowered from 20% to 10% in an update to the guideline a few years prior to my empirical fieldwork.

In Figure 21, the left of the snapshot consists of fields into which the patient’s dataset is entered (completed with as much information as is available at the time of calculation). On the right are the “results” including some suggested text which can be used to explain them: “Your risk of having a heart attack or stroke within the next 10 year is 10.1%. In other words, in a crowd of 100 people with the same risk factors as you, 10 are likely to have a heart attack or stroke within the next 10 years”. Patients like Mrs Green, coming to the Health Check to access medical insight into, and support for, their current health (in the context of the stresses and strains of everyday life) find themselves being orientated towards this statistically probability that they will have a heart attack or a stroke in the future, rather than their health as they know it now — similarly to how Dan’s GP tried to orientate his knowledge of his health needs (Chapter 1).

When Lydia talks about explaining “what that risk means” (EX21), she recognises that the risk score not only serves as an institutional tool for prioritising interventions, but that it should also be explained to the patient in accordance with guidelines. However, as highlighted in 6.5, explaining the risk score as a statistical probability was challenging for many HCPs. Some healthcare assistants were advised not to attempt this explanation and to leave it to the HCP delivering Part 2; others omitted, or fudged an explanation. However, even practice nurses and GPs found communicating probabilities challenging:

It's hard to give people these figures because it's a bit of an abstract concept [to tell someone] 'you've got 21% risk of getting a heart problem in the next 10 years'. For some people that might seem very low and others ...

EX22: Dr Abel

Here, Dr Abel appreciates that the number is an “abstract concept” and that it may be meaningless to her patients. Is 21% low or high? Does it reflect good or

bad health? The clinical guideline, CG181, makes various recommendations to guide HCPs in how they should explain the risk score to patients (Figure 22).

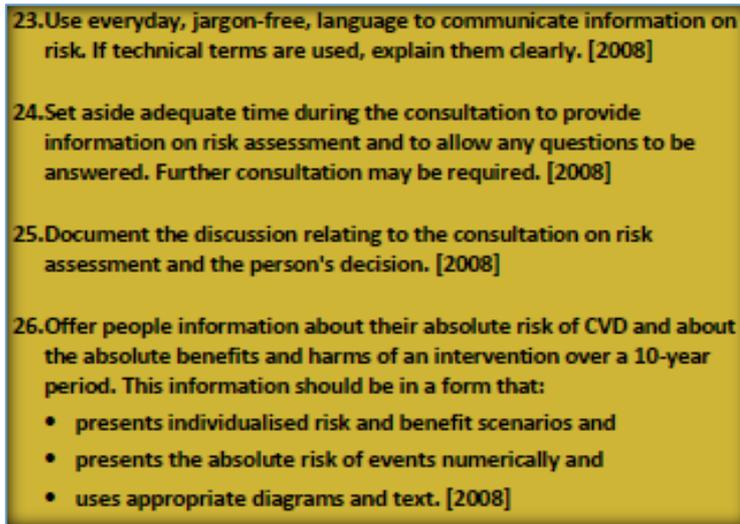
- 
23. Use everyday, jargon-free, language to communicate information on risk. If technical terms are used, explain them clearly. [2008]
24. Set aside adequate time during the consultation to provide information on risk assessment and to allow any questions to be answered. Further consultation may be required. [2008]
25. Document the discussion relating to the consultation on risk assessment and the person's decision. [2008]
26. Offer people information about their absolute risk of CVD and about the absolute benefits and harms of an intervention over a 10-year period. This information should be in a form that:
- presents individualised risk and benefit scenarios and
 - presents the absolute risk of events numerically and
 - uses appropriate diagrams and text. [2008]

Figure 22: Recommendations relating to communicating the risk score

These include using jargon-free language (recommendation 23), and presenting information “numerically and us[ing] appropriate diagrams and texts” (recommendation 26). An example of the type of diagram which might be used is provided in the Patient Decision Aid attached to CG181, an excerpt of which is shown at Figure 23.

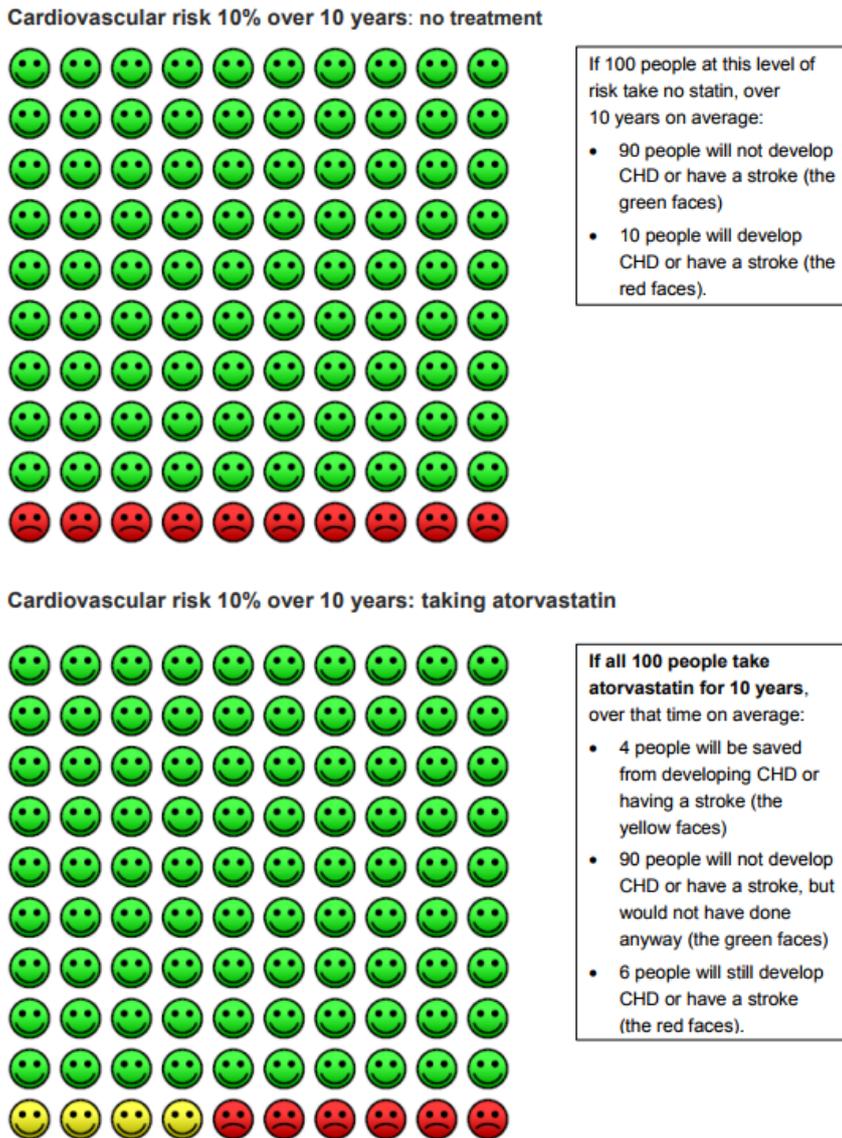


Figure 23: Diagram and suggested text for communicating risk and benefit of statin treatment, in Patient Decision Aid attached to CG181 (NICE, 2014i)

It is not my intention here to evaluate HCPs' adherence to the guideline's recommendations to incorporate particular techniques for communicating risk. However, it is noteworthy that HCPs were reluctant in interviews to detail *how* they communicated the risk score when I asked them to describe this practice to me. Most repeated a one-line form of words similar to those in Figure 21, but were not confident to explain any further; evidence from interviews and observations (including specific enquiries among proponents of the types of tools illustrated at Figure 23) suggested that HCPs were reluctant to attempt statistical explanations.

The purpose of diagrams such as that reproduced in Figure 23, is of course to bring population-based statistical probabilities to individual patient care. Figure 23 compares CVD outcomes (heart attack/stroke) if the patient has ‘no treatment’, with CVD outcomes if the patient is prescribed ‘statin treatment’. According to this illustration, four people “will be saved” from a CVD outcome in the next 10 years out of 100 people taking the statin (90 would not experience a CVD outcome whether or not they were on treatment; six unlucky ones would experience a CVD outcome in either scenario). Below, I discuss decisions about whether patients will be prescribed a statin, but first I suggest some explanations for why HCPs avoid explaining risk statistics to patients.

First, HCPs know that the concept of risk is not easily understood by patients, and does not translate easily into frontline preventive action; as Dr Abel says in EX22, a statistical probability about the future may not be meaningful to her patient. (This of course is why visual aids, such as the one depicted in Figure 23, have been produced to assist in risk communication.) Both the risk score’s statistical nature, and its population-level focus, however have the potential to cause problems when it ‘lands’ into the consultation. Although these problems appeared to be, in part, related to *interpretation of risk*, Dr Abel also highlights the different understandings her patients bring to the consultation of *what is important*. As I will show in 7.3 below, the risk score therefore presented a challenge to Dr Abel if it failed to precipitate the forms of action recommended within CG181.

Second, HCPs struggle with what the risk score means. Lydia, for instance, told me that she deliberately moves conversations away from the meaning of risk towards “what patients can do to change it”. This is both for the benefit of her patients, and because she too finds it difficult to explain if questioned. Although Dr Smart (whose account I foreground in greater detail in Chapter 8) is more interested in ‘the numbers’ than most HCPs, he also emphasised that both patients and HCP colleagues (GPs as well as HCAs) struggled with numerical concepts:

I don't think people talk about risk [...] Most patients are innumerate. If you say to somebody, 'You're at 30% ten-year risk', they don't understand. Scarily, substantial numbers of doctors don't understand. [...] If you ask doctors to convert one in a thousand to a percentage, it's something like twenty per cent can't do it and you just think, 'If you can't do that, how can you understand risk and how can you communicate it?' So innumeracy in patients is huge and we then bombard them with stats that they can't understand and doctors don't understand it.

EX23: Dr Smart

Here, Dr Smart combines different knowledges about communicating statistical risk — from frontline practice, from research evidence, and from discussion in his professional network. He articulates (as I had observed in other HCP accounts) that it is not only *patients* who struggled with statistical representation of risk, but also *HCPs*. As becomes clear later in this analysis, this problem relates not only to understanding probabilities, but also to applying guideline thresholds for intervention, which have little direct relationship to an established disease process (4.4.1).

Third, as I show in more detail in Chapter 8, providing a full explanation of the risk score and/or discussing how it might relate to their patient's individual circumstances and preferences has implications for HCPs' workloads. Although this is acknowledged in recommendation 24 (Figure 22), which tells HCPs to “set aside adequate time”, HCPs completing the Health Check work to fixed appointment schedules organised around the economics of delivering the checks.

As I will show in the following sections, HCPs' work is organised to focus on particular treatment outcomes. By avoiding probabilistic explanations of risk, HCPs skirt difficult queries from patients, do not need to understand the complexities themselves, and save valuable appointment time, allowing them to focus more single-mindedly on outcomes which are more institutionally important.

7.2 Acting on the risk score: “offering statins”

In this section, I show how HCPs draw on CG181's authority when describing how they act on a patient's risk score. In the following excerpt from my interview

with Dr Abel, she gives an account of delivering Part 2 of the Health Check, which involves talking to patients about their high risk score and agreeing a course of action. Her account provides clues about the institutional practices and social organisation of Dr Abel's knowledge that coordinates the Part 2 consultation, and provides a starting point for the analysis in the rest of this chapter.

If the risk is high then we would need to contact them to discuss whether they are willing to be on a statin or whether we just need some more lifestyle measures initially. Usually, if it's someone I've not seen (I mean most of the time patients have seen one of our nurses or Health Care Assistants for the Health Check [Part 1]), if I've not actually met them, I would then probably want them to come in to see me to meet me face to face and go through it. If it's someone where I've done a [Part 1] Health Check and met them I would perhaps do it over the telephone, do a consultation. So speak to them about their cholesterol result and what their risk is and what that sort of means for them.

Again that may prompt other things that they can be doing, so in terms of stopping smoking or weight loss. Or asking them about their diet (which again would have been covered to some extent in the Health Check [Part 1]), giving them dietary information on low-fat diets, and seeing if they do want referral to lifestyle [intervention] about their diet.

Then, if the risk is high, offering them a statin, which some patients are very keen to have [laughs] because they've heard that it helps to reduce the risk of heart events and stroke. Others have heard some of the more negative publicity about statins, or they've had a relative who's been on them and had bad leg-ache for example and don't want them. Some people want to try diet and exercise first and so we might agree to check it again in three months. And I do warn people that that doesn't always work. Some people just have a naturally high cholesterol and it is important that they do modify their diet, but it may not come down dramatically. [emphasis mine]

EX24: Dr Abel

Dr Abel's account is orientated around whether the "risk is high". She imagines a scenario in which she has already calculated the risk score by pressing the button

on the Health Check template, and determined that it is above a **threshold level of absolute risk** over which she should “offer statins” according to CG181. Although Dr Abel talks here about explaining what the risk score means, my data indicate that she was not referring to an explanation of probabilities, but to informing the patient that they were now categorised as being ‘at risk’. It is this new status (a quasi-diagnosis) which is her focus in the Part 2 consultation, rather than the “abstract concept” of risk itself. Although HCPs consistently emphasised to me that they “followed guidelines”, my data indicate that they routinely bypass probabilistic explanations as promoted in CG181 in favour of a more ‘diagnostic’ approach, simply activating the risk score as a diagnostic category of ‘at-risk’ (a simple binary category acting as a ‘diagnosis’ of a ‘condition’). In the following excerpt, Lena explains how she educates patients in relation to the meaning of risk thresholds during the Part 1 appointment:

I say to [patients] ‘the [risk score] is done for things that we need to look out for over the next 10 years. Whether you’re going to be probably more susceptible for heart attack, diabetes and stuff like that. That’s why you’ve come in. We try and keep [the risk score] under a certain amount, which is 20, but anything over 15 obviously we advise you to come in and see the doctor.’

EX25: Lena

Here, Lena fudges the meaning of the ‘abstract’ number (EX21), pointing her patients instead towards the categories of high/low risk to which she is working, and the possibility of medical intervention if their risk is ‘high’ (“seeing the doctor” for Part 2). She refers to the 20% risk threshold which had been modified in the 2014 update to CG181. (The update recommends that statins should be offered at risk scores at 10% or greater.) The shifting guideline category of ‘high-risk’ has created what Lydia describes as a “grey area” between national and local protocols; local commissioners and providers are having to catch-up, and manage the consequences of the change:

[Laughs] So, we follow the NICE guideline for lipid management which then leads us to a nice grey area because the old NICE guidelines were that if their risk was above 20%, then you would offer them a statin. The new NICE guidelines said if their risk is above 10%, then you offer them a statin. But then that hasn't actually been ratified by the CCG I don't think. So we're still going with the 20% risk cut-off. [...]

EX26: Lydia

When Lydia talks about whether the new threshold risk score (in national guidelines) has been ratified by the local CCG, she recognises that authoritative knowledge about patients' risk is a shifting knowledge, with thresholds for intervention moving in the light of new evidence of clinical benefit, and as a result of shifting healthcare economics — both nationally (4.3.1) and locally.¹²⁷ However, both Lena and Lydia position threshold values as the 'facts' upon which they should base medical management of risk. They attentively activate the risk threshold (at whatever level it is set) as a quasi-diagnostic cut-off point which, similarly to a physiological biomarker indicating treatment for a risk condition, guides them to a particular treatment for high-risk patients.

However, the risk threshold is more difficult to handle than a physiological biomarker in clinical consultations with patients; it does not directly connect to a single physiological condition or an established aetiology of disease, and so it is more difficult to explain. Although *all* clinical intervention is of course based on population-level, statistical evidence (from defined research populations), the risk score (and intervention with statins which promise to reduce risk) appear only ambiguously connected to a disease process within guideline representations; the threshold percentage, and the associated treatment recommendation, appear as 'abstract' — unrelated to a bodily reality. It is due to the distinctive probabilistic nature of 'overall risk' that communication tools such as in Figure 23 have been produced. Such illustrations are in contrast to the way HCPs have commonly

¹²⁷ Following this change in the guideline's threshold value from 20% to 10% approximately 18 months prior to these conversations, local health centres (under the direction of their governing CCG) had taken some time to adjust their practices, being mindful of both the constitutional imperative to deliver care according to the guideline, but also of managing the implications of the change on health centres.

communicated risk conditions through simple explanations of the physiology involved — using descriptions, for example, of cholesterol clogging arteries (see BMJ Group, 2016a). These more visual, and more comprehensible, explanations relate directly to bodily functioning, and imply that everyone treated will benefit, even though this is never the case for any medical intervention.¹²⁸ I return to discuss the tensions generated by the risk score from the standpoint of patients in 7.4.

The particular treatment to which the risk ‘diagnosis’ points is lipid modification therapy with statins, as I have already shown. Although CG181 outlines 96 recommendations, based on 302 pages of justification, covering many different elements of CVD risk assessment and management work, HCPs (e.g. Dr Abel in EX24) home in on the recommendation to **“offer a statin”** if the risk score is above a 10% threshold (recommendation 54); when HCPs state that they “follow the guidelines” (e.g. in EX26), further probing suggests that they seek to follow this single recommendation specifically, reflecting the Health Check’s textual sequence (Figure 20 p.146). In EX24, Dr Abel translates the recommendation to mean that she should **“discuss whether they are willing** to be on a statin”. She understands that she should use the conversation to check whether the patient will cooperate with this course of action. Although presented as a choice for the patient (or sometimes as a ‘shared decision’ between patient and HCP — see below), it is clear that the discussion which Dr Abel describes is directive; we see that she looks ahead to what the outcome of the consultation *should be*, assuming that the patient takes up the offer.¹²⁹

Dr Abel’s approach is connected to the institutional use of the term, “offer”, which derives from NICE’s technical wording used in recommendations. This is different to the way “offer” is used in common-parlance:

“Recommendations for activities or interventions that should (or should not) be used should use directive language such as ‘offer’ [...] NICE uses ‘offer’ (or similar

¹²⁸ Like the risk score, taking medication for any risk condition is also a matter of statistics.

¹²⁹ Note that Dr Abel points out in EX24 that she may “go through” the risk score over the telephone rather than face-to-face. The implication is that, if she thinks the patient will be “willing” to accept a prescription for statins (will not raise objections), she can complete this work very quickly over the telephone.

wording such as 'measure', 'advise', 'commission' or 'refer') to reflect a strong recommendation, usually where there is clear evidence of benefit. [...] Some recommendations are 'strong' in that the Committee believes that the vast majority of practitioners or commissioners and people using services would choose a particular intervention if they considered the evidence in the same way as the Committee. This is generally the case if the benefits clearly outweigh the harms for most people and the intervention is likely to be cost effective” (NICE, 2014d).

Although Dr Abel may, or may not, be familiar with the *technical detail* of guideline wording, she nonetheless activates the knowledge embedded in the guideline's framing of this decision about statins. She trusts that CG181's recommendation to “offer a statin” is based on “clear evidence of benefit”, and that taking a statin will be in her patient's best interest. However, although HCPs consistently refer to statin treatment as ‘evidence based’ or tell patients “statins will reduce your risk” (Dr Abel) (see also EX27 below), my data suggest that their knowledge of the evidence included in the guideline is very limited; instead they rely on CG181's authority to mediate knowledge of the most appropriate course of action.

The knowledge of benefit, described above and embedded in the guideline's use of the term “offer” is in tension with the statistical presentation of benefit presented in Figure 23. Here again is the disjuncture between traditional medical knowledge which (at least rhetorically) is supported by clear biological disease mechanisms, and knowledge of risk scoring which appears remote from this medical knowledge. The inclusion of risk scoring within NICE's existing technical framework however positions treatment of risk as treatment of any other condition; Dr Abel activates a diagnostic understanding when she “offers” the statin. Within this sphere of knowledge, which understands guideline recommendations to present “**clear evidence of benefit**”, HCPs know that people at ‘high-risk’ *should* be treated with lipid-lowering medications in order to prevent future CVD, and therefore that their work is life-saving — they are “stopping people dying” (see EX32, Chapter 8). Dr Abel's goal in the Part 2 consultation therefore is not only to offer statins (in a general sense of offering a choice), but to *demonstrate the benefit* of them to patients — an approach which resonates with the approach of Dan's GP in Chapter 1. As I show in the next

section, demonstrating the benefit of statin medications involves overcoming patients' 'barriers' to taking them.

7.3 Breaking down barriers to statins

When HCPs "offer statins" according to CG181's thresholds, they understand themselves to be delivering evidence-based care which is in the interests of their patients. As they work to establish (and perhaps generate) "willingness" from their patients (to keep them in line with CG181), they implicitly (or explicitly) appeal to the evidence base behind it. However, patients are not always "keen" to take statins (EX24) and HCPs therefore have to work to address their patients' concerns. Sometimes patients are confident to raise concerns. At other times, Lydia tells me, patients are reluctant to raise them; their concerns are the "**elephant in the room**" (see EX27 below). In this section, I consider these concerns, where they come from, and how these are understood and addressed by HCPs.

Continuing with Dr Abel's explanation of the Part 2 consultation in EX24, she tells me that she initiates a discussion with an agenda — "whether they are willing to go on a statin" (as above). This, she says, involves speaking to the patient about their cholesterol result and "what their risk is". As discussed in 7.1, this often involves bypassing statistical meanings of risk, and shortcutting to the recommended 'treatment' (statins) — and to whether the patient is willing to comply with it. Dr Abel mentions several commonly-raised queries about going on statin medications. The first relates to side-effects, and the second to whether they could avoid medications by making changes to their diet and exercise habits. Another common query (from interviews with other HCPs) relates to why cholesterol-lowering medications are being offered when their blood cholesterol result is within normal range (i.e. they have not understood the risk score, or how it is linked to treatment with statins) (see 7.2). This third concern intersects with concerns about side-effects as it relates to patients' understandings of how statins act in the body — understandings which are considerably informed through the media. Whatever the concern however, HCPs characterised the work involved in addressing such queries as "breaking down barriers":

*You have the barriers to start breaking down. So it's 'What do you know about statins?' 'What have you heard about statins?' 'How would you feel about taking them?' And then you explain to them what the side-effects are. If they have the side-effects then let me know because I will stop the tablets. It's up to them, they don't **have** to take them if they don't want to. It's going to reduce their risk, but I can't say for definite that it means that they won't have any problems. It has to be their choice, so you ... I [corrects herself], I don't ignore the elephant in the room.*

EX27: Lydia

Lydia here draws on common approaches to behaviour change, such as those embedded in motivational interviewing (e.g. Murray et al., 2012), which either directly or indirectly attempt to break down psychological barriers (Olson, 1992) (see 4.1). She asks her patient to open up about their preconceptions — “What do you know?” “How would you feel?” She then corrects them where their knowledge does not align with CG181, “explaining” for instance “what the side-effects are” (e.g. their nature, and the likelihood of experiencing them). Her description of this work as “breaking down barriers” is apt as she has a clear goal (statin prescription), and the patient’s concerns are obstacles to be addressed in order to achieve it. However, Lydia also recognises that tensions between her own (institutional) work to promote the benefits of statins, and the patient’s concerns around taking them, may not be easily negotiated within this short conversation. She activates a concept of ‘choice’ alongside the guideline recommendation, telling me that, once they have the information (and she has put the case for statins) patients are still at liberty to decline them — “it’s up to them, they don’t *have* to take them”. In the following sub-sections, I show in more detail how HCPs’ work to break down barriers, first highlighting patients’ wishes to attempt lifestyle change before accepting lifelong medications, and second their queries regarding what statins will do in their body.

7.3.1 Patients who want to “try diet and exercise first”

In EX24, Dr Abel ensures that she follows CG181’s instructions about promoting lifestyle change (e.g. advising patients to stop smoking or lose weight, questioning them about their diet, or offering a referral to a lifestyle intervention), but she also works to stop this becoming a distraction from statins. Although

HCPs told me that they consistently promoted lifestyle change, and that CG181's focus on statins did not detract from this commitment, their knowledge of patients who wanted to "try diet and exercise" before starting statins is that they are 'putting up barriers'. Building on her experience of people's unsuccessful resolutions to change their lifestyles, Dr Abel informed me that these patients had previously had many opportunities to change their lifestyle, and that they were therefore "unlikely to be more motivated" following a high risk score than they had been before. This meant that a patient's desire to make a renewed effort at lifestyle change was likely to be enthusiastically received by their HCP, but was primarily understood as a potential distraction from actively "reducing risk" through pharmacological intervention.

Dr Abel points to both her frontline experience of patients and to research evidence when she says "I do warn people that [lifestyle] doesn't always work". She does not mean that their lifestyle changes will have absolutely no benefit to their health, but that this benefit will not textually reduce their risk to a level which is likely to remove them from the high-risk category (and their 'need' to take statins). Although she recognises her patients' reluctance to go on a long-term medication, and their desire to make efforts to avoid this, she overlooks the opportunity to enter into a genuine patient-centred conversation, as presented by the risk discussion. Instead, she continues to focus on prescribing the statin, whilst allowing her patient to temporarily postpone the prescription. When she "agrees" with the patient to check their cholesterol result again in three months, this is from an authoritative position which anticipates that 'knows' that she will eventually prescribe the statin — but which allows the patient time to come to terms with their need for preventive intervention.

Similarly to Dr Abel, Christina (healthcare assistant) tells me that she works to help patients to "resign themselves" to medications, whilst positively encouraging them to work on lifestyle change:

I think we are lucky here because doctors do give patients the opportunity to air any concerns and ask questions and if somebody is a bit 'hmm I don't really want to go on statins' doctors will say 'well let's go and see Christina for some dietary advice and we will check it again in 3 months'. Some people unfortunately, just kind of have to resign themselves to the fact that they need a statin. [...] In my experience patients don't like it when you say 'look if you don't stop this, if you don't start doing this you are going to die because you are 70 now', you know you can't dictate to people and [say] 'you must do this or have that [medication]'.

EX28: Christina

Christina reports that the GPs at her health centre expend effort on supporting patients who want to “try lifestyle”; they may for instance internally refer patients to Christina for lifestyle support which is not specifically funded. However, even in this context, Christina knows to help patients recognise that they “*need a statin*”. Although she is gentle about it (being careful about both her words, and that she does not “dictate”), the ruling relations of risk management coordinate her knowledge of individual risk and its treatment. She unwittingly activates the ruling relations when she sidelines her patient’s preference not to take statins; her work is directed instead towards helping them to “resign themselves” to statin treatment whilst simultaneously recognising that the disjuncture generated needs to be smoothed-over carefully.

7.3.2 “Media myths”

Just as Dr Abel attributed patients’ concerns about side-effects to “negative publicity” (EX24), Lydia in the following excerpt attributes concerns about how statins work to “media myths”.¹³⁰

¹³⁰ Lydia mentions the following which require explanation:

Gloria Hunniford: TV/Radio Presenter and producer of a ‘healthy living’ video, who was hired as a Flora margarine ‘brand advocate’ on a series of TV ‘infomercials’ (Smith, 2009).

Flora pro-activ “produces a range of products clinically proven to lower cholesterol” (Smith, 2009).

‘Know your numbers’: a campaign originating with the American Heart Association (American Heart Association, 2017), but which has been widely promoted in the UK by charities and companies with commercial interests relating to high blood pressure or high cholesterol e.g. (The Best of Health, 2016).

"So then I explain to the patient (because Gloria Hunniford has done a good job with selling Flora Proactive and 'Know your Numbers' for cholesterol. So they all think it matters what their cholesterol is. Which really, in the long scheme of things when you look at that risk assessment that's just one tiny marker out of a whole load of other things). So I have to explain that it's looking at your blood pressure, it's looking at your weight, it's looking at your sex, it's looking at where you live, it's looking at your family history, it's looking at your cholesterol. So [cholesterol's] just one marker. So it could come back and you think it's fine at five, but your risk could be 25 so we would offer you the statin. So you have to start wading through the media myths around that risk assessment."

EX29: Lydia

Lydia tells me that patients' concern with cholesterol, rather than overall risk, is the result of "media myths" and she particularly highlights the role of the food industry (e.g. manufacturers of cholesterol-lowering foods) in this misconception. Her work, as she describes it, is to "wade through" these myths — to correct patients' understanding. She does this not by explaining cholesterol's role in the development of CVD, or by discussing the significance of statins in reducing overall risk, but by framing a stronger imperative to action; the risk score is taking account of their *whole life* and therefore deserves even greater attention.

When patients bring alternative understandings or queries to the consultation, we see here that HCPs may characterise these queries as "media myths", which should be patiently corrected, rather than as valid objections to be discussed and addressed on a case-by-case basis and in the light of patients' individual, constantly-shifting situations. Patients hooked into an evolving and controversial research evidence base (albeit filtered through news reports); controversy surrounded both the evidence that *lay behind* CG181's recommendation, and also *additional* evidence which emerged as new research studies were reported and new controversies arose (4.4). Nonetheless, it appeared that HCPs consistently reframed these queries according to ruling knowledge about the role of guidelines. Within this frame of knowledge, CG181's recommendation to "offer statins" is based on "clear evidence of benefit" (7.2). Discussion of the evidence itself, or how this might apply to the individual, are subjugated as HCPs refuse,

or are unable, to engage in more complex discussions about the evidence or more individualised discussions about its application. (The social organisation of HCPs' attention to 'following guidelines' in relation to preventive medications becomes clearer in Chapter 8.)

7.4 From the standpoint of patients: 'Does it make sense to take a statin?'

As HCPs work, they draw their patients into other connected forms of work (Rankin and Campbell, 2009). Patients work to respond to the offer of statins, having to consider, and then choose, what to do. They raise queries and then have to respond to HCPs' correctives. Patients do not view their queries as putting up 'barriers', nor as reflex responses to media myths, but as engagement with what they have heard about statins — and often as reasoned attempts to weigh up whether statins will benefit them, whether there are other valid alternative approaches to addressing their risk status, and what the personal consequences are for their own lives. Clearly not all patients have the desire, or the ability, to research these issues. However, my data suggest that patients often look for personal reassurance from their HCP that preventive medications are *generally beneficial* (in the light of research evidence) and, more importantly, that they are likely to benefit *them individually*, (in the light of their own personal health). One patient, to whom I talked 'in passing', summed up his own work to weigh the options and engage his GP in the process, when he told me that he was uncertain about the level of benefit he would get from them, and wanted his GP to tell him whether statins "**make sense**" (from a clinical perspective). Although he was already taking statins (based on his GP's recommendation), he was still in the process of weighing the benefits against the side-effects. Although he had been told that statins were 'evidence based' and 'recommended', were they really so important? What did his GP's assurance that they were 'evidence-based' mean for him when faced with unpleasant side-effects? These questions become particularly pertinent when confronted with individual considerations about taking them.

Many study informants had been offered statins. The discussion which ensued with the HCP was greatly affected by their relationship, and by the patient's own ability to present their needs in particular ways. In the remainder of this section, I

cut just a small window into some of the work patients undertake to resist statins, showing that it can be difficult for them to do so. The aim of this section is to provide readers with a view of the diversity of patient accounts, not to categorise them into different types or groups. For reasons of space and coherence, and because the purpose of this chapter is to highlight institutional relations (not patient typologies), I highlight some experiences in relation to talking about statins, but do not attempt to extensively evidence with data excerpts. Instead, I return quickly to the social organisation of these divergent experiences in 7.5. The following sub-sections briefly describe some of the work involved in ‘choosing’ whether to take statins.

7.4.1 Negotiating with HCPs

Some patients, such as Bernard and Barak, “come to an agreement” with their GPs that they will not take statins; they report assertively presenting their case. They talk about how their relationship with their HCP facilitates this — for instance “my GP knows what I think”. Although older than most of my informants, both Bernard and Barak appear fit and healthy. They have both worked to find out how much benefit they are likely to get from the statin (both with the cooperation of their GP, and through other sources). They have therefore been able to confidently assert that they prefer not to take them, that they understand the risks, and that the (small and inherently uncertain (probabilistic)) benefit is not worth the detriment of taking daily medications. They both also draw on knowledge which makes them confident to act contrary to the recommendation, and are able to clearly articulate this to their GP. Bernard for instance highlighted his genetics, which he did not think was adequately captured by the QRISK2 calculator (making him lower risk than the calculator suggested). Barak on the other hand emphasised the quality of his lifestyle, telling me about the importance of diet and exercise, and the health benefits associated with stress relief (such as he experienced through practising yoga) and quality relationships (again not captured within the algorithm).

Both Bernard and Barak had done most of the work involved in weighing up the offer of statins outside of the consultation room, and were able to present a ‘decision’ which clearly asserted their ‘preferences’. In Chapter 8, I show that, by actively taking responsibility for the decision themselves, these patients make it

easier for their HCP to *account* for a course of action which goes contrary to guideline recommendations.

7.4.2 Overcoming clashes with HCPs

Other informants start to take statins but experience problems after experiencing, and then reporting, side-effects. It had taken Jane many months to attribute her thrush symptoms to statins, and she had then struggled to persuade her GP that they were the cause of the problem; her symptoms did not fit with the side-effects indicated in the guideline. She was only “allowed” to stop the statins, she says, after persistently returning to the GP, trying several different brands, and then (finally) being confident to assert that she did not want to continue with them. Similarly, Julia had taken statins for many years and reported worsening health problems (complicated by another condition). In desperation, she had researched the side-effects of her medications, decided to attempt a trial period of not taking them, and found that she was no longer “in chains” with her aching muscles. She had, however, had a heated argument with the receptionist at the health centre who had called her (following a blood test) to “tell her off” for not taking her medications. When she had then asked her GP for help with her diet to order to reduce her blood cholesterol, she reported that the GP had been abrupt and simply handed her a diet sheet.

Sarah struggled with multiple medications for T2DM in addition to the statins. Similar to Julia, she had not recognised side-effects immediately, but had become so depressed with her declining wellbeing, including the side-effects of Metformin (a diabetes medication), that she had abandoned the statin when she had heard from friends that it could be contributing to her symptoms. When I observed her ‘diabetic review’ (4.2), the practice nurse checked that Sarah was taking the statin as she proceeded through the review template. Sarah quietly pointed out that she had stopped taking them, but avoided a discussion about her reasons for her unilateral action. Afterwards, Sarah told me that she had been reluctant to raise the issue because she was worried that the nurse would try to persuade her to continue with the statin; she did not want the relationship to suffer as a result of contravening the nurse’s advice. It was noticeable that patients like Sarah, and the others mentioned above, had taken on board that their HCP would be reluctant to facilitate a course of action which was contrary to guideline

recommendations, and they understood that the clinical relationships on which they relied could suffer if they went against them.

7.4.3 Resigning yourself

Another group of patients, such as Naomi, Dean and Silv, do not actively resist taking statins, but express their dislike of taking multiple medications (for a risk condition in addition to their high risk status). It was clear to me that they had (willingly or unwillingly) “resigned themselves” to statins, along with an array of other medications (see Christina’s comment in EX28). As the Community Centre Manager in Wildwood had told me, the area is full of “unhealthy specimens”, whose general health status and socioeconomic circumstances create all kinds of difficulties; these patients’ lives were dominated by preventive medications. Dean, for example, arrived to see me at the community centre in smelly clothes and with a huge plastic bag full of medications for his T2DM, gout, and of course statins. Similarly, as I talked with Silv, and noticed the custard creams scattered over the floor (of which granddaughter and dog had already had their fill), I was conscious of the packets of medications piled high on the tiny kitchen surface, of which the statins were just one.

These patients’ diets are full of low-cost, processed ‘junk foods’, they do virtually no physical activity apart from short walks to the shops, and yet their lives revolve around medications as they work to comply with the required regimes. Statins are just another pill among the many others. As these informants have little medical understanding, they rely on HCPs to advise them. Like Naomi, who worked to take medications to avoid getting “told off” and maintain much-needed relationships with HCPs, these patients may make efforts to follow medication regimes, presenting no objections to taking the pills if this is the recommended action.

The examples above are just tiny glimpses into patients’ diverse responses to the offer of statin medications. These are all organised however within the same set of ruling relations in which HCPs work to persuade patients following calculation of a high risk score. Both HCPs and patients work to bridge the gap between authoritative evidence about statins, and patients’ understandings of the role of statins and their application to their everyday lives. As I have shown, HCPs did this by discounting and correcting knowledge which fell outside CG181’s

authoritative stance. Some patients, particularly those with access to alternative sources of knowledge, are able to challenge the simplistic representation of statins as clearly beneficial to them. Many however have significant difficulty in raising concerns and/or making a decision which fits well with their everyday life. Although the analysis presented in this chapter is focused on statin mediations (which, as I have shown, enter into HCPs' work within a very particular textual formulation of patients' overall risk), my data suggest that similar work may be involved when medications are recommended to treat specific risk conditions.

7.5 Involving patients or pushing medications? 'Shared decisions' in practice

In this chapter, I have highlighted HCPs' work to promote statins following a 'high-risk' diagnosis, and patients' coordinating work to discover whether they make sense in the light of their own individual circumstances. In this final section, I briefly consider how HCPs *characterise* their work with patients who are found to be at 'high-risk', and how they think about the authority of clinical guidelines, on which they drew in order to persuade patients of the benefits of statins. Do they experience tensions in their own practices which reflect those experienced by patients? In 3.1, I highlighted that some GPs *do* experience disjunctures in their own practices. GPs in the Preventing Overdiagnosis (POD) movement, for instance, highlight the uncertainty surrounding the scientific evidence for statin treatment and, what they consider to be, an increasing clinical 'culture' in which HCPs uncritically apply guidelines. Drawing on the work of academics such as Greenhalgh et al. (2014), they highlight a shift in the focus of clinical practice from knowledge of the patient (as an individual), to a more remote epidemiological knowledge.

However, as I have already shown in this chapter, many HCPs do not recognise this view of their own preventive practices. Whereas many in the POD movement stressed the potential side-effects of medications, and raised concepts of 'medicalisation', many HCPs (such as those interviewed in English-region) draw on a dominant knowledge of risk management (Chapter 4) understanding that promoting statins for the treatment of a high risk score is good clinical practice. I discussed these apparently dichotomous ways of understanding preventive practices with Dr Sully, a vocal proponent of Health Checks in English-region. In

the following excerpt, he responds to my suggestion that HCPs might, perhaps inadvertently, be putting patients on medications which do not fit well with their everyday lives, or benefit them as much as either HCPs or patients imagine (based on data presented in Chapter 8). Dr Sully's response illustrates what Smith (e.g. 2005b, p.155) describes as 'ideological' or 'institutional capture' (3.5); he subordinates his knowledge from "being there" (Rankin, 2017a) (his situated knowledge of what it means to promote 'openness' and trust in a conversation) in favour of an alternative ideological knowledge:

The whole gist of this is to get into a position where you can have an honest and open conversation with the patient, with information that you need to make a decision. [...] The idea to suggest that we're sort of there to push medications is stupid and I don't accept that at all. It is about actually informing the patient, helping them to make an informed decision about their own life. The evidence behind what we do is absolutely top drawer. In terms of treating people's hypertension, treating diabetes, treating cholesterol, no one would argue [...] so you know, it's about having a conversation with a patient and saying 'these are the guidelines, we know this works, these are the benefits and these are the risks, you decide'. It's not about piling medication on.

EX30 Dr Sully

Dr Sully emphasises here that the whole point of the risk score is to have an "honest and open conversation with the patient" (the kind of conversation for which Naomi and Dan appealed). He is familiar with current debates, but he adamantly refutes my summarised version of some HCPs' concerns, telling me that he is not "there to push medications".¹³¹ By contrast, his work, he says, is to provide the best evidence-based information, so that patients can make an "informed decision" about the 'benefits' and the 'risks'. Dr Sully's comments confirm what I have seen in practice; he considers that his work to explain the benefits of statins (and to promote their use) is part of, and entirely compatible

¹³¹ This is *his* expression, not suggested in these strong terms by me, but perhaps reflecting debates in which he has been involved (see EX32).

with, supporting his patients to make an “informed decision”. The idea of “pushing medications” in an aggressive manner is anathema to him, and he does not recognise this characterisation of preventive practices. He therefore presents the Part 2 consultation as an “honest and open conversation” which will lead to the patient making “an informed decision” based on their own preferences. During interview, he added in strong terms that this “conversation” was entirely “patient-led” in relation to whether patients pursued lifestyle approaches, statin treatment or (ideally) both. He repeatedly emphasised that he “involves” patients, and that the decision about whether to accept a prescription for statins is “up to them”; mirroring Lydia’s approach, he underlines that they have a free choice. However, the knowledge of patients’ needs on which Dr Sully draws is (as articulated here) almost entirely through institutional texts, which assure him that guidelines represent the ‘best evidence’ (“we know this works” he says); therefore their recommendations will provide the clinically ‘best care’ for his patients.

Unfortunately, as described previously, I was unable to observe these Part 2 conversations. However, other data presented in this chapter suggest that the “conversation” which Dr Sully mentions usually involves a much more one-way interaction than the term “conversation” implies. An HCP informs the patient that they are ‘at-risk’ and that a statin is recommended to ‘reduce their risk’ — accompanied with usual caveats about possible side-effects. The HCP then checks if the patient has questions, addresses any ‘barriers’ if necessary, and confirms with them that they are ‘willing’ to start this new medical regime (EX24). The Part 2 consultation is seen as simple and unproblematic, often being carried out over the telephone in a shorter time than a routine appointment (EX24).

The knowledge practices described make complete sense within the risk management discourse: HCPs provide the information; patients make a choice based on their particular preferences. The answer to the question ‘does it make sense to take a statin?’ is emphatically ‘yes!’ The Part 2 interaction therefore appears simple and obvious, particularly as statins are understood to have few (and reversible) side-effects (e.g. Gupta et al., 2017). However, I have shown that the ideological practices embedded in the Health Check leave behind other knowledge of the uncertainties surrounding statin medications and their impact on patients’ lives, and they leave little room to support patients to improve their

health. Dr Sully's account of the Part 2 consultation as an "honest and open conversation" leading to an "informed decision" also subjugates what he likely knows from his own frontline experience — that patients expect (by and large) to do what their HCP recommends, as indicated by the common question, "what would you do doctor?" (e.g. Charles et al., 1997; Sokol, 2007).¹³² His approach, although ostensibly offering options, is likely to be interpreted by patients as a directive to take medications, especially when accompanied by HCPs' attempts to 'break down barriers'; it overlooks the many queries and issues which patients raise in relation to taking preventive medications.

7.6 Tracing the concept of 'patient involvement'

The notion of 'involvement' on which HCPs draw can be traced directly to ideas embedded in CG181 and elsewhere about 'risk communication', 'engagement', 'participation', and 'taking account of [patients'] values and preferences' (a group of ideas all relating to 'involving' the patient). Going back to Dr Abel's account in EX24 (p.179), she not only tells me how she needs to check her patient's willingness to take a statin, but she also integrates CG181's recommendations about *how* she should work (collaboratively) with the patient. For example, when she says that she speaks to the patient about "what their risk is, and what that sort of means for them", she refers to recommendation 27, which includes the instruction to "find out what, if anything, the patient has already been told about their CVD risk and how they feel about it". Other examples include asking "about their diet", or "if they want referral" (see Figure 24). These activities all relate to what is authoritatively known as 'engaging' or 'involving' the patient.

¹³² "Non-compliance" with treatment regimens is often unintentional (e.g. Vermeire et al., 2001; Jin et al., 2008).

22. NICE has produced guidance on the components of good patient experience in adult NHS services. These include recommendations on the communication of risk. Follow the recommendations in Patient experience in adult NHS services (NICE clinical guidance 138). [new 2014]

27. To encourage the person to participate in reducing their CVD risk:

- find out what, if anything, the person has already been told about their CVD risk and how they feel about it
- explore the person's beliefs about what determines future health (this may affect their attitude to changing risk)
- assess their readiness to make changes to their lifestyle (diet, physical activity, smoking and alcohol consumption), to undergo investigations and to take long-term medication
- assess their confidence in making changes to their lifestyle, undergoing investigations and taking medication
- inform them of potential future management based on current evidence and best practice
- involve them in developing a shared management plan
- check with them that they have understood what has been discussed. [2008, amended 2014]

48. The decision whether to start statin therapy should be made after an informed discussion between the clinician and the person about the risks and benefits of statin treatment, taking into account additional factors such as potential benefits from lifestyle modifications, informed patient preference, comorbidities, polypharmacy, general frailty and life expectancy. [new 2014]

50. Before offering statin treatment for primary prevention, discuss the benefits of lifestyle modification and optimise the management of all other modifiable CVD risk factors if possible. [new 2014]

51. Recognise that people may need support to change their lifestyle. To help them do this, refer them to programmes such as exercise referral schemes. (See Behaviour change: individual approaches [NICE public health guidance 49].) [new 2014]

52. Offer people the opportunity to have their risk of CVD assessed again after they have tried to change their lifestyle. [new 2014]

53. If lifestyle modification is ineffective or inappropriate offer statin treatment after risk assessment. [new 2014]

54. Offer atorvastatin 20 mg for the primary prevention of CVD to people who have a 10% or greater 10-year risk of developing CVD. Estimate the level of risk using the QRISK2 assessment tool. [new 2014]

Figure 24: Key recommendations from CG181 which appear in EX24

Activating concepts of 'involvement', however, turned out not to produce the types of experiences implied by language in CG181 such as "encourage", "communicate" and "inform". HCPs' practical application of recommendations for 'involvement' is at odds with CG181's more idealistic definition of 'risk communication' as "the open, two-way exchange of information and opinion about risk, leading to better decisions about clinical management". In practice, HCPs' 'conversation' work is organised to involve short questions or statements, whose content and terms are directly derived from CG181's recommendations (i.e. in a semi-standardised format). These 'guideline refrains' (such as 'guidelines recommend that you should have a statin', 'What do you know about statins?', 'These are the benefits...') prime patients for medications by ensuring that HCPs quickly elicit 'barriers' and make attempts to 'overcome' them.

Notions of involvement in CG181 should be understood then, not according to colloquial understandings of the words and phrases involved, but as having institutional meaning constructed within CG181 itself and within broader social relations. Not only is 'involvement' an important part of providing a good 'patient experience' (NICE, 2012b), but it has a specific institutional goal: to promote adherence to statins; involving patients will result in "better decisions" through which patients will be "more likely to adhere to their chosen treatment plan" (NICE, 2014f). Although a patient's treatment plan can (at least theoretically) involve lifestyle change instead of statin medications, or avoid any action at all to address risk, the coordinating textual organisation of the term 'involvement' is clear.

CG181 emphasises that, within the coordinated practices of risk management, 'adherence' to statins is of considerable importance.

"The development of statins has been heralded as an important advance in the primary and secondary prevention of CVD. Adherence to statin treatment has however been shown to decrease over time. [...] Adherence in the real world is substantially worse than that seen in clinical trials. Adherence with statins declines over time and a significant proportion of patients stop taking their statin within 2 years of initiation. Patients with high adherence are less likely to be hospitalised than those with lower adherence" (NICE, 2014f)

The solution to this problem is authoritatively understood to lie in ‘involving’ (or ‘communicating’) with the patient:

*“One of the main strategies for CVD risk management is the use of lipid-lowering therapies, especially statins. Statin therapy needs to be a long-term treatment to be fully beneficial. Key challenges in the field of CVD prevention include [...] **convincing people** who feel well that they need to make substantial lifestyle changes and need lifelong drug treatment. **High-quality information and communication on the benefits and risks** associated with these therapies are needed.”* (NICE, 2015a) (*Emphasis mine*)

In EX24, Dr Abel draws her patients into actively “choosing” the institutionally sanctioned course of action, to which (according to the behavioural theories on which CG181 draws) they will be more likely to adhere. Dr Abel’s account demonstrates that, although CG181 is a single guideline, it is formed from multiple recommendations which are organised into a unified whole with an institutional purpose to start ‘high-risk’ patients on lifelong medication. When HCPs activate these recommendations, they blend mundane uses of language such as ‘patient-led’, ‘communication’ and ‘involvement’ with their institutionally-sanctioned cognates (see 3.2) which bring with them the institutional agendas of compliance with standardised forms of risk reduction (2.6).

The Part 2 consultation ends with a decision about whether, or not, the patient will be prescribed medications.¹³³ A decision about statins, for instance, is recorded using a drop-down menu on the electronic template, and provides an important trace of how such decisions are socially organised and a thread to follow into Chapter 8.¹³⁴ Dr Abel emphasises that, if a patient declines statin treatment, it is important that this should be recorded on the electronic record:

¹³³ This chapter has focused on decisions about statins following a ‘high-risk’ score. Other decisions about medical treatment for newly-identified risk conditions such as hypertension or T2DM are also made at this point.

¹³⁴ Patients choosing not to take statins are recorded using a code indicating “statin unsuitable” or “informed dissent” (Primary Care Commissioning, 2014; NHS Digital, 2016a).

*"You obviously have to have that discussion with them about the pros and cons of treatment and **record it on the notes** if they have declined statin treatment. Or we have some people who go on statins for a while and then want to come off them when they don't like the side effects. And again that's then communicated to them about the risks and benefits of treatment and **making sure that's clearly documented.**" (emphasis mine)*

EX31: Dr Abel

Not only should the decision be recorded on the drop-down menu, but it should also be "documented" in free-typed notes which make clear that the risks and benefits have been "communicated to them". In Chapter 8, I follow this thread to show the institutional work involved in documenting medication decisions, attending particularly to the practices of HCPs who facilitate decisions which go contrary to guideline recommendations. I shine a light up into the ruling relations which shape the knowledge, the practices and the difficulties shown in this chapter — ruling relations which organise HCPs to understand their work one way, while it is experienced quite differently from a patient standpoint. I turn my attention to the accountability practices of frontline HCPs and local policymakers which help to explain why HCPs so keenly promote preventive guidelines and may struggle to implement more nuanced and patient-orientated practices of 'shared decision-making'.

Chapter 8 Facilitating ‘meaningful conversations’

This chapter extends the empirical analysis of chapters 5-7. I have previously shown how, although HCPs’ prevention practices are understood institutionally to ‘engage’ or ‘involve’ patients in looking after their health, they frequently organise distance or discord between HCPs and patients, as HCPs work towards institutional goals which clash with patients’ own knowledge of their preventive care needs. Even when patients appear to be ‘on board’ with preventive action, they may experience significant tensions between their own desire for good ‘care’ and the preventive care provided. I have shown, based on an analysis of what happens at Health Checks, that HCPs actively disengage from the everyday problems which are real to people and which impact on their health, whilst promoting medications as ‘evidence based’ solutions to reduce risk. Patients are channelled into particular forms of preventive work in which the prescription of unwelcome pharmaceutical interventions takes precedence over adaptive support for people to make changes to unhealthy behaviours.

In this chapter, I return to the concerns of activist GPs highlighted in Chapter 3. These concerns, often expressed in abstract or philosophical terms (e.g. ‘harms’ of prevention; ‘overdiagnosis’; or debates about the tyranny of clinical guidelines), formed the original catalyst for this study. These GPs consciously frame their commitments to patients differently from the HCPs whose accounts form the basis of analysis in Chapters 6 and 7 (although their concerns overlap). My attention is not on the characteristics of these GPs as a categorically distinct group and ‘different’ from the majority of ‘jobbing GPs’ (or others involved in delivering or managing preventive care). Rather, the difficulties they experience as they try to practice differently (to ‘swim against the tide’) particularly highlight ruling relations, and enable me to further develop this explication of the social organisation of preventive care. I focus on their accounts of their frontline clinical work, and particularly their work to engage in *meaningful conversation* with patients over their preventive care needs. As I will show, these GPs experience ongoing tensions (seemingly mirroring some of the tensions experienced by patients) between their understanding of what constitutes ‘good care’, and the ruling preventive practices into which they feel themselves being drawn. I show some of the extensive work involved in adjusting their work around authoritative

textual processes, in order to practise in a way which (they argue) is more collaborative with their patients, and therefore better ‘care’. This work takes place not only during patient consultations but also behind the scenes of frontline care where they have to mitigate against the potential reputational and financial consequences of their practices. I show that HCPs’ local practices are coordinated through performance metrics which are collated nationally and are taken up by local policymakers in order to monitor health centres and drive improvements. These metrics feature prevalence and treatment data for risk conditions and are important textual coordinators of the “intertextual complex” (Rankin and Campbell, 2006, p.121) orientated to reducing textual constructions of the ‘burden of CVD’ (Chapter 2). I show how management techniques which involve benchmarking, variation modelling, and aligning various financial incentives are used by local policymakers to reinforce the importance of these metrics and orientate HCPs’ work to them. Although HCPs may attempt to modify and adapt their work in the interests of their patients, *even their resistance is organised* within the strong scaffold of GBD discourse.

8.1 The QOF in general practice

In 2.6, I briefly introduced the QOF whose impact on general practice has been both substantial and controversial (e.g. Steel and Willems, 2010; Langdown and Peckham, 2013). Although its scope has receded in recent years, and it is expected that (at some point) it will be replaced with an alternative mechanism, it is still a crucial part of practice income, especially in the context of considerable funding constraints (see Roland and Guthrie, 2016 for more details of the QOF system); a significant proportion of general practice income is based on performance against a set of performance indicators.^{135,136} In 2016/17, for instance, there were 77 indicators for which a maximum of 559 points could be achieved (NHS Digital, 2016b); each point was worth £165.18 (NHS Employers,

¹³⁵ Originally, general practices could earn up to 20% of their income from the QOF (Guthrie et al., 2006).

¹³⁶ The QOF’s future was in doubt throughout the course of this study. It has been unpopular with GPs because of indicators which contradict their ideas about good clinical care. However, an acceptable replacement has not yet been found (Marshall and Roland, 2017).

2016b). The indicators which directly relate to CVD prevention are listed at Appendix 4 (as extracted from the GP contract (NHS Employers et al., 2015)).

I will not unpick the full complexities of the funding arrangements, but a few examples of how the system works are relevant here. It is important to recognise that health centres receive points (linked to payments) for both *maintaining registers* of patients with particular conditions, and for intervening with particular *treatments* — primarily through prescribing medications. For example, points are available for prescribing anticoagulants to a particular group of atrial fibrillation patients. This is an important element of the textual organisation of, for instance, Dan's experiences, as discussed in Chapter 1 (EX1). Although the QOF funding formula is complex (health centres do not need to prescribe anticoagulant medications to *every* individual in order to achieve maximum points for the AF006 indicator¹³⁷), points are forfeited if the *overall proportion* of (for example) atrial fibrillation patients receiving anticoagulant medication falls below a specified threshold (70%). For the treatment of risk conditions such as T2DM, pharmaceutical interventions are incentivised in a somewhat more ambiguous way. For example, points are awarded when these patients' blood sugar levels, blood lipids, or blood pressure are documented to be below particular threshold values. I show in this chapter that, although these values may (in principle) be achieved through a range of lifestyle changes (not just through medications), HCPs know medications produce these QOF 'outcomes' far more reliably and quickly than is likely to be achieved through lifestyle change alone.

It is relevant to consider at this point how the practice of risk scoring relates to the QOF incentive system. (In Chapter 7, I showed how the risk score was an important technology within the Health Check sequence, and how HCPs promoted statin medications to patients.) It is noteworthy that prescribing statins is *not* financially incentivised through the QOF for all patients who are diagnosed as being at 'high-risk'. Prescription of statins is incentivised *only* for a group of patients newly diagnosed with *hypertension* (CVD-PP001) who are *also* found to be at high-risk. Statins are also incentivised *indirectly* for patients with T2DM

¹³⁷ The system incorporates flexibility for a proportion of patients to decline medications.

(DM004). As mentioned above, a target blood cholesterol is most readily achieved with statins. These are technical details, but it is important to understand that there is not a direct and linear relationship between *QOF incentives* and HCPs' practices relating to risk scoring. Analysis later in this chapter will further explore the complex social organisation of the practices highlighted in Chapter 7.

8.2 Bad-guy-gone-good: pursuing a different kind of 'patient-centeredness'

The analysis presented here begins with Dr Smart's account of changing his approach to clinical practice (EX32). This was as a result of multiple epiphanal moments in which he had encountered other GPs who were challenging the status quo, and attempting to practise 'differently'. He uses the concept of 'patient-centred care' to characterise how he now aspires to practise, emphasising that being 'patient-centred' in his view is in *direct contrast with* 'following guidelines' (his characterisation of how he previously practised). This is a *different* conceptual view of patient-centeredness from that used by informants in Chapter 7 to support patient compliance with guideline recommendations. Here, Dr Smart draws attention to tensions in his work which GPs such as Dr Abel had not acknowledged. This extended excerpt provides a fascinating insight into one GP's intellectual and emotional wrestling in order to carve a professional identity which challenges institutional structures. I will come back to key aspects of Dr Smart's account throughout this chapter.¹³⁸

¹³⁸ Several aspects of Dr Smart's account may require explanation:

"Comms skills" refers to communication and consultation skills training provided through a variety of routes, most notably through the GP training programme (Health Education England, 2014).

Ben Goldacre is a prominent campaigner against "bad science" (Goldacre, 2018).

Informant: "I'm a poacher-turned-gamekeeper, or a bad-guy-gone-good. Instinctively I'm black-and-white, logical, do-things-by-the-book. So when I started in general practice, I was very much for following guidelines, abiding by the rules. When the QOF came out in 2004, I was highly enthusiastic. I thought it was great. I thought the targets would bring up standards across General Practice and it was right up my street. It was everything I could hope for. Then disappointingly for me, for years I thought it was really good. I still believed it was a good thing, and then here were a few things that turned me round and I went full-circle. Spending more and more time as a trainer and training GPs in comms skills, I began to realise that the skills we were training them for when they're not necessarily for following the guidelines, a lot of the comms skills is about what do patients want, patient-centeredness, and that didn't square.

[A GP associate] was ahead of me saying that the QOF was rubbish. We were doing things to people. We weren't asking them what they wanted or for any views. We were just pushing medications onto them. And he and I used to fight, you know, just about it, argue for hours on, 'Yes but you're not considering this. People are dying. They're not on the statins they should be. They've not got their HbA1cs to target. This is good medicine.' So I began to question whether what I was doing was actually right, and the more time I spent thinking about it, the more I felt at a visceral level that my biggest conviction in General Practice is patient-centeredness, that's what matters. Matters more than outcomes. Well it depends what the outcomes are, but actually my job is to allow my patients to make decisions for themselves.

continued on next page ...

Interviewer: Is that what you see as being the essence of patient-centeredness?

Informant: Yes. Yes. I think it's for my patients to be in control to the extent they wish to be, over what happens to them. So I see my job as partly facilitative to try and help them find out what it is they want, to give them the information to make those decisions, to support them in those decisions and to try and make sure those decisions are implemented and not run roughshod over. Joining the Overdiagnosis Group about two years ago hit me at a time when I was beginning to question a lot. I'd seen Ben Goldacre³ talk about three years ago and he confirmed everything what I knew really about big pharma, the influence of that. I began questioning how reliable trial data was. 'How do I know this is true?' So inside my head there was a big questioning about accepted wisdom and an increasing feeling that I wanted to challenge it and ask, 'How much of this is actually true and how much of it fits with what I believe in?'

EX32 Dr Smart

Dr Smart challenges the very significant changes to frontline work which have been managerially engineered in recent years. Central to these changes has been the introduction of the Quality and Outcomes Framework (QOF), which was designed to improve the quality of care (especially prevention and management of chronic disease) in general practice by incentivising particular activities, already established in clinical guidelines. These changes have had a profound influence not only by appealing to GPs' financial motivations, but also directly positioned as supporting the good clinical practices of EBM. In EX32, Dr Smart refers to his previous practice (even *before* the introduction of the QOF) as characterised by “*enthusiastically*” following guidelines; he was committed to good practice, not as bureaucratic rules to be followed but understanding this evidence based work as directly averting death — activating a risk management discourse which emphasised ‘saving lives’ (see chapters 2 and 4). This guideline-focused knowledge of good practice had been bolstered by the new QOF ‘outcomes’ — the performance metrics to which he, and his health centre, are now held accountable. These are the measures by which his (apparently) life-saving work is represented textually in order that it can be monitored, and ‘improved’ from a distance. Although these measures often appeared only

fleetingly in HCPs' accounts of their work (and many HCPs were unfamiliar with the detail of how their health centre's activity was textually monitored and financially incentivised), this chapter highlights that metrics nonetheless shape frontline practices.

Dr Smart's view is that HCPs' work has become generally orientated to the QOF's system of targets and incentives, through which they understand themselves to be improving standards of care through "following guidelines". "Following guidelines" ("abiding by the rules") is a euphemism for what could also be described more candidly as 'following incentives'; it is clear from his account that it is *financial* targets through the QOF which he particularly understands to influence HCPs' practices and "bring up standards". (The QOF had been implemented because guidelines on their own had not previously produced these standards.¹³⁹) Dr Smart describes here his previous confidence in, and zealous application of, the textual products of the institutional complex, which he had previously characterised as 'good medicine'. His trust in the evidence led him to "argue for hours" with a professional associate,¹⁴⁰ warning him that, because he was not prescribing statins to enough patients, "people [were] dying"; he had understood his associate's restraint in prescribing to be poor (or even negligent) practice. The QOF's financial targets blur into his conceptualisation of "good medicine", which incorporates scientific research evidence, guidelines — and now financial incentives.

Dr Smart's observation of changes in his own clinical practice following the introduction of the QOF now leads him to understand these changes not as improving the quality of care, but as promoting practices in which GPs like him are "doing things to people" as they shift their attention away from patients' individual needs towards activity which will 'count' in QOF accounting at the end of the financial year. "Doing things to people" he indicates involves the kinds of practices which I had observed and heard about in Chapters 6 and 7 — a subtle

¹³⁹ HCPs frequently characterised their work as 'following guidelines' when referring to the requirements of the computer template. They were particularly orientated to financially-incentivised activity, which was highlighted within the template.

¹⁴⁰ A GP friend who was involved in managing a health centre elsewhere.

(or not so subtle) “pushing medications onto people” (EX32) as HCPs activate a risk management discourse promoting ‘evidence based’ treatments to reduce patients’ risk (see EX27).¹⁴¹ Although Dr Sully, for instance, had vigorously denied that he “pushed medications” onto his patients (Chapter 7), I have shown that HCPs’ preventive practices are sometimes experienced by patients as “pressure” to comply with medication regimes which are *difficult to fit*, or which they *do not want to fit*, into their lives (see Dan’s story EX1 in Chapter 1). In 8.3, and continued through the rest of this chapter, I explore in more detail how incentives and other performance measures enter into HCPs’ (and especially GPs’) work. Before moving on to this more substantive analysis, I highlight a couple of important aspects of activists’ such as Dr Smart’s accounts.

First, Dr Smart draws on the concept of ‘patient-centred care’ to assert what he now understands to be “good medicine”, and to challenge a characterisation of typical clinical practice — “following guidelines” (EX32). Patients, he argues, should be the focus of his work, but instead his work is orientated to the QOF’s ruling texts, embedded in electronic templates at the frontline. His discursive activation of ‘patient-centred care’ provides an(other) illustration of how a ‘shell term’ may be activated. Here the term ‘patient-centred care’ is filled with Dr Smart’s local knowledge about what being ‘patient-led’ should involve whilst, in the mouths of others elsewhere, the term is employed (filled) with a management agenda (see 3.2). By ‘patient-centeredness’, Dr Smart does not mean adhering to ruling notions of ‘patient centred care’ as textually constructed in, for example, the NICE Patient Experience guideline — practices which “involve” patients but with a built-in goal of a patient’s compliance with the guideline advice proffered (7.5). Instead, he refers to “facilitative” work in which he attempts to “help [patients] find out what it is they want” (EX32).¹⁴² This is a process of *uncovering* preferences which are at first not obvious to patients themselves, and which may

¹⁴¹ Not egregious failings (c.f. the ‘harms’ caused by medical ‘errors’ which are more frequently the focus of healthcare improvement activities).

¹⁴² Dr Smart’s increasing sense of what constituted ‘good care’ was based on: delivering communication skills training which focused on prioritising patients’ concerns; his reflection on his own practice; and his experience of “what patients want”. Although training such as ‘communication skills’ for GPs are an important part of ruling relations, it appears that such efforts may be subservient to more dominant social relations, such as those shown in this chapter.

run contrary to guideline recommendations and associated financial incentives. It involves ongoing work in which he will need to “support [patients] in those decisions” by making sure that decisions are “implemented and not run roughshod over” (by ruling practices, to apply IE’s theoretical approach to his comments). Dr Smart understands his patients’ wishes as frequently running contrary to the standardised texts embedded in guidelines, and as liable to be contravened — perhaps by himself at another time, or perhaps by another HCP who treats the patient. However, the ‘patient-centred care’ which he advocates is “what matters”, he says, and is the morally “right” way to practise medicine.¹⁴³

Second, it is important to recognise that Dr Smart’s and other activists’ challenges to ruling relations are shaped by those ruling relations. In EX32, Dr Smart questions *whether clinical guidelines can be trusted* — whether they conform to accepted terms of scientific validity (‘the truth’). He mentions the malevolent influence of the pharmaceutical industry (‘big pharma’) in the institutional complex producing research evidence and clinical guideline recommendations (as prominently highlighted by, for example, Goldacre, 2013). Evidence in guidelines, he suggests, may not be quite as scientifically robust as he had thought and therefore should not be uncritically accepted as the ‘truth’. Nevertheless, activist GPs, as others, have to work within existing structures of knowledge, and rely on the evidence provided to them in guidelines. When they talk about what it means to be ‘patient-centred *in practice*, they focus on the “low clinical effect” of interventions, rather than on their concerns about the production of research evidence:

¹⁴³ When Dr Smart talks about decision-making in EX32, he draws on understandings of SDM *which align with* his ‘ethical’ notion of patient-centred care. Like the concept of patient-centred care, SDM too is activated somewhat differently by activist GPs to how it was applied by HCPs in Chapter 7.

I mean my interest in overdiagnosis was piqued initially by realising, having spent some time really going through guidelines, that a lot of the recommendations that I'd been slavishly following were based on evidence of very low clinical effect, so good quality evidence, but interventions weren't as valuable as I thought they were.

EX33 Dr Stefan

Here, Dr Stefan (another activist GP) *does not directly challenge the validity of the evidence itself* (as seen in the debates outlined in 4.4) but instead draws from *authoritative knowledge* about the quantified benefits of medicines such as statins (as produced in guidelines — see for example Figure 22), and emphasises that this medication may have only a very small, or no, benefit to the individual patient. This approach is compatible with Dr Stefan's work in various non-frontline roles (e.g. in leadership / on guideline committees) in which it is very difficult to challenge the scientific evidence itself, but in which he is able to legitimately challenge and influence key *texts* and *practices* using established discourses (e.g. EBM, risk management).¹⁴⁴

Challenging ruling relations from *within* the dominant risk management discourse, Dr Stefan proposes that patients should be provided with more information on the “scale of benefit” of interventions and suggests that HCPs will have to “suck it up and accept that things will get a bit more complicated” as they will need to access new resources and learn new skills (e.g. statistical numeracy) in order to present statistical information within the clinical consultation, and work out which research applies best to their individual patient. Even basing his arguments on established evidence is not easy however; he is drawn into methodological analysis and discussion of individual research papers. In the same way that I showed patients' work being drawn towards interrogating the evidence base (7.4), activist HCPs too are pulled into detailed critique of the evidence which lies behind guideline recommendations, in order to counter a risk management discourse frequently activated simplistically as “[medications] will reduce your risk” (7.2). However, it

¹⁴⁴ Some activist informants attempted to exert influence through involvement in healthcare work away from the frontline — including, for instance, sitting on NICE committees.

is important to note that their activist challenge to dominant scientific knowledge is nonetheless *shaped* by the rationalities of the risk management discourse, as they operate its mode of knowledge and its scientific formulations of ‘truth’ in order to re-present the evidence in a way which provides more *detail* about the value (and the limitations / uncertainties) of preventive medications.

8.3 Orientating to the QOF in frontline practice

I now go on to show in more detail how the textual management technologies of guidelines, incentives and performance metrics, enter into HCPs’ work – even when these HCPs formulate their work as a rebellious form of patient centred care. When Dr Smart talks about ‘outcomes’ (EX32), he specifically refers to ‘QOF outcomes’. Health centres rely on QOF income; opportunities to earn QOF points are highlighted within the electronic templates attached to the patient record so that HCPs know to pay particular attention to them — “they come up in pink boxes, it’s like someone shouting” (Dr Smart). In the following example, Dr Smart invokes a typical patient (‘Mrs Smith’) in a consultation.

Mrs Smith comes in who weighs eighteen 18 stone and does no exercise and her cholesterol’s 6.5 and her blood pressure’s a 160/95, and we’re wondering about a statin and we’re wondering about antihypertensives. Actually the issue is, ‘Well Mrs Smith, your weight and your lifestyle is contributing significantly. There are things we can do to get your risk of problems in the future down. This is the spectrum of options.’

EX34 Dr Smart

When Dr Smart considers how to consult with Mrs Smith, he is organised to activate knowledge that links him to the QOF system; certain clinical activities will earn QOF points for the health centre. Mrs Smith has ‘established hypertension’ and has therefore been put on the QOF ‘hypertension register’, for the maintenance of which the health centre receives points (indicator HYP001). Another indicator (HYP006) incentivises Dr Smart to ensure that Mrs Smith’s ‘last blood pressure reading is 150/90 mmHg or less’. As she is ‘newly diagnosed’, there are points for calculating a risk score, and ensuring that, if it is >20%, she is ‘treated with statins’ (indicator CVD-PP001). If Dr Smart also weighs Mrs Smith,

calculates her BMI, and discovers that it is >30, he can also add her to the ‘obesity register’ (indicator OB002); even though there are currently no incentives to ‘treat’ obesity, points are awarded for keeping the register. Drop-down menus of options ensure that these activities, when recorded correctly using the right electronic codes, contribute to the calculation of the health centre’s QOF performance. ‘Read codes’ (NHS Digital, 2017) also provide specific search tools that allow data in the electronic system to be extracted, and reports produced. In the excerpt below, Dr Smart describes how the QOF system incentivises him to prioritise medical treatment.

If I've got a target for cholesterol, I know that if I stick you on a statin, you'll hit that. Statins, I mean we may moan about them but they're really really [effective], they deliver a low cholesterol absolutely predictably in everybody that takes them. As long as you take them, your cholesterol will come down. [...] If I start sending you off, putting you on perhaps a diet, trying to increase your exercise, trying to get your weight down, that may bring about benefits, but it may take several years for you to turn that round, for you to start showing some major changes. If I want to hit my target, put you on a statin, do your blood test in four weeks, you'll be treated to target.

EX35 Dr Smart

If Dr Smart works to support Mrs Smith to change her diet or to exercise, it may take a long time for this to have an impact, even assuming that she throws herself into this work. It is this knowledge which Dr Swift (also an activist GP) emphasised when he told me that he and his patients (*together*) have achieved unprecedented success at implementing lifestyle change through an approach which places the patient “absolutely central” (see EX38 below). Dr Swift’s approach involves encouraging his patients to set their *own agenda* for their prevention work — an agenda which frequently involves *immediate* and tangible reasons to change lifestyle habits (such as *feeling* better, or being able to participate in a particular activity), rather than being directly motivated by *avoiding death*. His approach resonates with a patient’s assertion that “it’s the **quality** of life that counts isn’t it?” (interview with Sarah).

Indeed, in the pursuit of a good *quality of life*, I have shown that patients sometimes seek to implement lifestyle changes in order to *avoid medications* (see Dan's story for instance) — and it is this motivation to which Dr Swift appeals. Rather than referring his patients however to locally-commissioned lifestyle interventions (the recommended approach), he himself works directly with patients who show an interest in making changes. He discusses their diets in detail, and encourages patients to return for follow-up appointments and to attend an in-house weight-management group (which he set up himself). Having seen patients be successful at losing weight through low-carbohydrate approaches (see 4.4.3), he advocates for the approach, emphasising their success stories. He tells me of the importance of optimism backed up with tangible guidance on exactly which foods to change in an individual patient's diet. Using continuity from one appointment to the next, he gradually educates his patients where they show enthusiasm to make changes, monitoring and responding to their attempts over time. Dr Swift's approach challenges the ruling authority of targets focused on achieving particular targets, for instance for blood pressure, sugars, or cholesterol (Appendix 4). Another GP (Dr Jack) expresses a similar concern about the impact of preventive targets:

Do we try so hard that they end up being poisoned by all the volumes of pills that it takes to reach the target? Because it becomes a law of diminishing returns. You get most of the benefit from that first pill or first intervention and then adding in another one, and another one and another one, becomes less valuable and more harmful.

EX 36: Dr Jack

Dr Jack knows that, although medications can be very effective (EX35), sometimes lifestyle change is much more effective; relying on medications alone causes all kinds of side-effects as the number of medications required increases, and they interact with each other. However, as Dr Smart points out, approaches which emphasise and support lifestyle change may take many months to bear fruit (if at all):

I don't [habitually] open conversations about weight in consultation, because I know if it's going to be a meaningful conversation it's going to take me 15, 20 minutes at least, whereas you can prescribe in two minutes.

EX37 Dr Smart

If the GP gets involved with patients' efforts to make changes, this may impact on their ability to demonstrate good performance or have implications for their appointment schedule. Dr Smart tells me that the appointment time will have to be considerably longer in order to have a "meaningful conversation" with the patient (EX37), who will then potentially require subsequent follow-up appointments. As a result, Dr Smart tells me that (although he wants to be 'patient-centred') he *still does not routinely open conversations* about lifestyle with patients.

As highlighted above, Dr Smart's practices are not free from social organisation by virtue of his changed attitudes to "good medicine". If he wants to hit his QOF targets for the current year (i.e. quickly and within the resource constraints of the health centre), the most reliable means of doing so is to prescribe medication (EX35).¹⁴⁵ Patient-led practice, which involves "meaningful" (sensitive) discussion of issues like weight and a patient's overall health goals, clashes with the textual organisation of his work. Targets are time-limited; they need to be accrued quickly. Being 'patient-centred' will involve not only involve time for the patient to undertake their own health improvement work, but will also require additional time for him to consult with them. Even though he aspires towards a different kind of practice to his 'jobbing GP' colleagues, he is still (and knowingly) orientated towards the measurable 'outcomes' which can be achieved much more easily through medications (especially within the significant resource constraints of general practice).

¹⁴⁵ Dr Smart refers here to indicator DM004 which requires that cholesterol should be below a 'target level' of 5mmol/l for patients on the 'diabetes register'. High risk patients with a new diagnosis of hypertension should be 'treated with statins' but not to a target level (CVD-PP001).

When HCPs facilitate outcomes which are contrary to guideline recommendations (e.g. supporting lifestyle change, delaying/avoiding pharmaceutical intervention), this may impact on their health centre's overall income (and therefore their own personal income as business partners):

I decided broadly that I am no longer interested in money, and that with the end of my career I will do what I think is right from the experience [of many years], and that I will try and place the patient absolutely central to most consultations and go from there. What I've discovered, fascinatingly, is that the experience of medicine is so much better because I am working with them.

EX38 Dr Swift

Dr Swift talks about consciously changing his moral focus away from reputational and financial interests embedded in ruling relations in order to do what he thinks “is right” — i.e. with the “patient absolutely central”. He knows that this approach has the potential to impact his personal income, and that of the health centre overall. Fortunately, he had found that his “experience of medicine [was] so much better because he [was] working *with* [patients]” (emphasis his) and, for him, this had compensated for the threat to his health centre's finances.¹⁴⁶ Nevertheless, Dr Swift, Dr Smart, and other GP colleagues continue to rely on the system of targets for a significant portion of their income and for indicators of their own, one another's, and their health centre's performance.¹⁴⁷

8.4 Risking reputations: healthcare managers' use of QOF metrics

In order to practise differently, activist GPs not only have to consider the *financial* implications, but also put their *reputations* on the line — to become “a bit of a maverick” as Dr Swift described it. QOF metrics do not only determine health centres' *income* but are also one of the primary means by which CCGs and other

¹⁴⁶ If Dr Swift prioritises a certain form of practice over his health centre's finances, this will affect not only himself but others at the health centre.

¹⁴⁷ GPs could, if they wished, monitor their colleagues' performance against the same indicators using publicly available data, and other internally circulated data.

governing organisations *monitor health centres' practices, and target improvement activities*. Indeed, CCGs are themselves held accountable in relation to the performance metrics of health centres in their regions, as I will go on to show. When Dr Smart talks about facilitating decisions which contravene a guideline's recommendation to prescribe medication, he appears to be troubled most by *how his professional performance is perceived*:

I love hitting targets and I'm really good at hitting targets. And it's increasingly important that you hit the targets because that's how you're perceived within the CCG. And then for the CQC, 'how are you doing on the QOF?' So to actually hit these targets is quite important, and we can do it. So I feel torn. I'm thinking, 'Oh shit. My diabetic figures are really bad and we're coming up to the end of the QOF year. I need to sort out a few more people.' So the temptation is there to push people to do stuff that you wouldn't feel you need to do.

EX39 Dr Smart

Dr Smart knows that “hitting [QOF] targets” demonstrates his health centre's performance, and by extension his own personal competence within his professional network. Now, although he challenges his past deference to 'outcomes', and attempts to re-orientate his work, his practice is nevertheless still articulated to these ruling relations. In the excerpt above, he brings to mind a familiar situation in which he looks up his current QOF performance statistics on the electronic system. He feels “torn” by the performance that it shows, and worries about his figures. This then organises his clinical work with individual patients, tempting him to “push them to do stuff”. He illustrates how GPs are pulled into spending appointment time on things that are not (in his view) clinically indicated or most relevant to the patient. Dr Smart says:

*I saw a woman yesterday, a diabetic, 87. She came to me [to talk about her anaemia], but we hadn't checked her feet, the circulation in her feet. So I stuck her on the bloody couch, checked her pulses were fine, you know, at the end not because it was clinically indicated, and it wasn't in the slightest bit appropriate, but I know that our figures are down, and she would be another one towards the target. [...]
We're getting towards the end of the QOF year, so it was either now or never.*

EX 40 Dr Smart

Even for those GPs who are critical of the practices that performance metrics generate, QOF metrics may influence them to 'stray' from the type of practice to which they aspire — to use their time in ways that do not fit their knowledge about each individual patient. The treatment of a patient such as this elderly diabetic woman (and Mrs Smith, EX34) is shaped by institutional relations which pull their GP into prioritising measures that contribute to the health centre's performance record.

'QOF work' is a major undertaking in general practice, particularly towards the end of the financial year. GP managing partners often divide this work between themselves during the year, allocating themselves each a particular element of the QOF for audit and improvement work, and enlisting support from administrative staff. At Wildwood health centre, this work is supported by a dedicated 'QOF administrator' who continually monitors QOF performance and ensures that 'QOFable' work is recorded. (The delicate 'back office' work of QOF coding is ethnographically described by Swinglehurst and Greenhalgh (2015).) As Dr Smart consciously commits to practice in a more 'patient-centred' way, his work is simultaneously drawn into checking the impact on these performance metrics. Aware of the implications of his philosophically-driven practices on his health centre's performance and his own personal reputation (which he was not willing to completely sacrifice in the way Dr Swift suggested in EX38), he has taken personal responsibility for QOF at the practice; he monitors his health centre's overall performance, ensuring that his HCP colleagues accurately record 'QOFable' activity (i.e. work which will contribute to QOF metrics) by using the correct drop-down codes on the electronic record to achieve points. Dr Smart's commitment includes efforts to record this activity on his colleagues' behalf, by

trawling non QOF-compliant patient records and adding coding where this reflects activity which has already been carried out — but is not recorded correctly. Ironically, this cooperative attention to QOF metrics is particularly important in a health centre where the partners seek to make the patient “central” (EX38), facilitating medication decisions which are sometimes contrary to guideline recommendations. In order to ensure that these (non-compliant) patients (and the electronic records which represented them) do not significantly affect the health centre’s income or reputation, health centre managers and GP partners need to be *even more vigilant about ensuring that other ‘QOFable’ activity (from other patients’ records) is fully recorded*. This ensures that the *overall proportion* of patients treated (within a particular QOF indicator) does not appear as anomalous to organisations with governance oversight (see 8.2) and that they are still able to ‘allow’ patients latitude over medication decisions (see below).

In the following sections, I look in more detail at how HCPs construct the health centres’ overall prevention work to fit with textual performance measures within the QOF system, and how this information is then used to monitor and drive ‘improvement’ from a distance.

8.5 Becoming an ‘outlier’

QOF outcomes are made publicly available by Public Health England (e.g. 2016d), and scrutinised by various governing agencies including the local CCG. In this section, I focus particularly on how these performance metrics shape the care of patients who have been diagnosed with a risk condition. (I come back to the Health Check and how its textual processes intersect with the QOF system in 8.6). Figure 25 shows how Public Health England presents the metrics gathered from health centres to compare them with each other, and also against the England average which acts as a ‘benchmark’. Different colours in each square indicate whether the health centre is ‘lower’, ‘similar’ or ‘higher’ when compared to the benchmark.

		Health centres within the CCG																																								
		Indicator	Period	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035	2036	2037	2038	2039	2040	2041	2042	2043	2044	2045	2046	2047	2048	2049	2050			
Demographic data	% aged 5 to 14 years	2016	115	128	150	210	138	108	150	154	4.8	13.5	12.2	9.9	10.2	3.4	10.8	12.6	13.8	2.9	8.8	9.1	14.6	10.4	12.8	13.0	13.0	13.1	13.7	15.2	17.3	15.4	0.1	15.1	0.4	15.4	13.0	14.1	12.6			
	% GP registered population	2016	20.7	23.6	26.8	26.4	24.7	20.3	26.4	26.1	13.7	23.9	21.2	18.3	22.7	14.1	18.0	22.4	21.2	12.4	18.8	18.4	29.2	18.1	21.6	24.8	23.7	24.0	24.3	26.1	28.8	26.4	1.9	28.7	10.2	27.2	24.7	25.6	22.3			
	% aged 65+	2016	17.2	11.1	9.1	8.0	10.7	15.0	10.7	8.5	2.7	10.0	13.5	15.6	8.9	1.3	23.5	12.1	8.6	1.4	9.3	12.4	12.8	16.1	13.6	10.2	14.7	11.4	9.7	10.5	12.3	14.1	0.9	9.3	1.2	6.5	11.2	15.9	14.2			
	% aged 75+	2016	7.8	5.1	3.4	2.9	3.0	7.4	8.9	3.6	0.7	4.9	6.4	7.3	2.9	0.6	12.5	9.3	3.2	0.4	4.1	5.5	6.9	7.5	5.7	4.8	6.7	8.9	3.6	5.1	6.1	0.5	20.0	4.1	0.4	2.1	5.2	7.2	6.2			
	% aged 85+	2016	2.3	1.5	1.2	0.9	2.3	2.4	0.9	1.0	0.1	0.8	1.5	2.3	0.5	0.2	4.3	1.5	0.7	0.2	1.2	1.7	1.7	2.1	1.4	1.4	2.0	1.3	0.8	1.2	1.7	2.1	0.0	1.0	0.0	0.3	1.5	2.1	1.8			
	Deprived (15-19)	2015	21.9	33.1	28.5	24.3	14.7	27.8	38.7	32.3	34.7	33.5	29.4	16.3	34.7	28.9	14.3	29.2	32.3	22.7	29.0	33.2	31.8	27.8	26.8	38.9	32.4	22.6	31.2	35.1	51.4	30.1	39.5	25.0	35.9	33.4	33.8	39.0	31.3			
	Deprived (10-19)	2015	21.5	32.1	30.4	25.1	12.0	27.9	39.2	33.1	37.4	33.7	30.6	14.7	38.4	30.0	15.3	33.0	32.9	21.5	25.7	32.5	33.0	29.9	27.7	34.7	31.7	22.0	34.1	30.0	51.3	29.8	39.8	25.1	38.0	35.8	31.2	38.4	31.8			
	IDAC1 (People)	2015	10.9	28.4	21.8	19.7	11.8	23.8	33.9	23.4	25.4	24.4	21.9	15.4	23.1	25.6	13.3	23.5	23.7	20.7	25.5	27.3	24.8	20.5	20.3	32.9	27.9	19.5	22.8	27.7	38.7	25.3	20.7	21.4	31.5	23.7	25.6	34.0	28.4			
	IDAC2 (People)	2015	15.2	31.5	39.2	31.3	14.2	20.9	29.7	45.3	34.5	47.7	41.8	19.6	34.9	37.2	16.2	35.7	45.5	26.7	29.5	29.4	35.4	40.3	34.8	29.6	23.5	20.9	43.8	44.1	38.7	30.1	39.5	33.9	38.9	49.0	29.5	23.5	27.7			
	% who practice	2015/16	78.0	86.6	82.9	88.8	88.7	74.4	88.4	91.5	82.6	73.1	71.8	58.0	75.2	90.4	91.7	87.4	88.3	89.7	85.0	83.1	80.8	42.8	47.7	77.5	66.3	78.6	57.6	65.3	70.2	67.4	84.0	49.1	68.7	65.6	62.8	64.2	60.4			
% satisfied	2015/16	72.9	68.2	62.5	69.6	77.6	80.8	58.4	62.8	74.0	67.9	65.2	61.5	61.2	80.0	60.1	80.0	70.5	72.4	80.3	82.4	80.0	62.6	64.8	64.1	46.1	75.8	54.8	60.1	70.3	62.5	31.0	56.0	64.1	72.2	56.5	77.5	61.2				
% satisfied	2015/16	75.9	70.8	69.1	74.9	83.8	75.3	80.2	91.8	80.1	91.8	87.7	70.1	70.0	68.1	91.0	70.3	69.2	70.9	74.7	91.9	80.0	69.1	80.0	78.3	71.0	74.9	65.3	70.8	62.9	71.1	67.7	70.1	83.9	78.2	80.4	82.9	72.9				
% who same or	2015/16	50.2	62.4	62.1	46.5	51.0	61.4	70.3	62.8	63.4	70.1	53.2	68.7	66.8	68.8	84.5	73.6	84.4	68.5	62.0	60.3	42.3	62.5	63.5	65.4	60.6	73.7	70.6	67.9	66.6	80.0	63.2	58.6	65.3	68.8	79.2	40.0					
% report	2015/16	73.4	68.4	62.2	61.3	74.0	75.5	68.2	81.5	75.1	68.5	61.4	74.2	66.7	83.4	77.4	59.8	73.0	74.6	61.4	62.9	62.6	44.4	70.6	62.2	70.7	54.4	66.2	72.0	91.8	31.3	66.3	64.8	73.3	50.2	62.6	60.6					
% with	2015/16	33.2	33.0	27.3	33.1	25.9	46.1	54.4	48.5	53.9	47.8	44.4	64.7	46.5	51.4	53.0	52.4	52.0	67.7	45.7	46.9	44.4	50.0	52.4	45.9	51.2	20.7	12.2	14.1	4.8	13.5	18.3	25.0	17.0	18.4	11.3	28.1	14.4	16.9	18.8	21.0	19.7
% with caring	2015/16	52.9	62.4	62.4	75.7	61.3	70.7	62.5	65.0	65.9	75.7	77.8	84.0	65.0	62.4	60.7	60.7	61.0	7.8	72.6	25.6	61.2	64.4	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0			
Working status - Paid work or full-time education	2015/16	82.9	82.4	82.4	75.7	61.3	70.7	62.5	65.0	65.9	75.7	77.8	84.0	65.0	62.4	60.7	60.7	61.0	7.8	72.6	25.6	61.2	64.4	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0	61.0			
Working status - Unemployed	2015/16	17.1	17.6	17.6	24.3	38.7	38.1	39.1	34.9	34.1	24.3	28.3	15.7	14.8	17.1	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6	17.6			
Total QOF points	2015/16	95.5	94.4	94.0	90.7	99.0	99.2	98.5	100	99.7	100	99.4	91.7	99.0	95.4	100	99.9	99.1	95.5	78.9	80.5	90.0	91.5	100	97.0	99.5	97.8	96.1	100	97.7	94.6	95.0	90.5	94.4	97.4	88.0	95.3					
Life expectancy - MSAO based (Male)	2010-14	79.4*	-	-	-	79.3	77.0	-	-	-	78.8	-	-	80.0	-	-	-	-	-	-	-	78.5	-	-	77.6	76.2	-	-	78.4	-	-	-	-	-	-	76.0	77.1	-				
Life expectancy - MSAO based (Female)	2010-14	83.1*	-	-	-	84.1	81.5	-	-	83.3	-	-	84.1	-	-	-	-	-	-	-	-	83.2	-	-	82.4	81.7	-	-	80.5	-	-	-	-	-	81.1	81.9	-					
Nursing home patients	2014/15	0.6	0.4*	0.0	0.5	0.3	0.2	0.0	0.2	0.0	0.0	0.0	0.2	0.0	0.4	0.2	0.1	0.1	0.0	0.2	0.4	0.7	0.2	0.0	0.4	0.3	0.7	0.0	0.0	0.9	0.9	0.0	0.1	0.0	0.0	0.8	0.0	0.1				

Figure 25: Practice Summaries for a CCG area, ‘Fingertips’ National General Practice Profiles (Public Health England, 2016d)

QOF data for each indicator can be called-up in different formats. For instance, Figure 26 (below) shows health centres’ performance in relation to indicators in the domain ‘Risk factors for CVD’, and how they are benchmarked against, for instance, another CCG or national average.¹⁴⁸ Using such tabular and graphic approaches, governing organisations have the capacity to monitor each geographical region and each of the health centres within it.

A textual process allowing HCPs to ‘exempt’ a patient from a particular indicator is built into the QOF system in recognition of frontline HCPs’ need to be able to adapt treatment to an individual patient — i.e. that a particular recommended treatment may not fit with an individual patient’s needs or preferences. In order to ensure that a patient who declines recommended medications does not negatively impact on the ability of their health centre to score QOF points, the HCP must ‘exception report’ them. However, the ‘exception rate’ for each

¹⁴⁸ There is some discrepancy between the indicators in Appendix 4, and those appearing on the National General Practice Profiles website. This is because some indicators still appeared on the website, although having been ‘retired’ from the indicator set.

indicator is also captured in performance metrics (see Figure 26 “exception rate” indicator).

Indicator	Period	England	Health centres within the CCG											
			NHS Leicester City	C82099 - All Wicqas	C82100 - All Wicqas	C82610 - All Wicqas	C82611 - All Wicqas	C82612 - All Wicqas	C82613 - All Wicqas	C82614 - All Wicqas	C82615 - All Wicqas	C82616 - All Wicqas	C82617 - All Wicqas	
Hypertension: QOF prevalence (all ages)	2015/16	13.8	11.8	11.6	6.9	15.2	14.7	12.7	13.2	5.3	15.0			
Exception rate for hypertension indicator (since 2014/15)	2015/16	3.9	3.8	3.8	17.9	3.0	2.0	3.4	4.5	5.9	1.9			
Exception rate for the BP indicator	2015/16	0.5	0.5	0.8	4.4	0.6	0.2	0.1	0.2	1.2	0.0			
Obesity: QOF prevalence (16+) - retired	2014/15	6.0												
Obesity: QOF prevalence (16+)	2015/16	6.0								9	7.0	8.7		
CVD-PP: QOF prevalence (30-74)	2015/16	6.0								6	0.4	0.8		
Estimated smoking prevalence (QOF)	2015/16	18.1	18.9	10.6	11.7	12.6	21.5	23.8	7.7	30.0	13.2			
Exception rate for smoking indicators (for indicators 2014/15 onwards)	2015/16	1.0	1.4	1.4	4.6	1.1	0.6	0.9	1.0	1.7	0.9			
GP patient survey: smoking prevalence	2015/16	16.4	17.7	13.8	13.2	14.7	22.5	20.4	6.3	31.7	14.4			
GP patient survey: ex-smoking prevalence	2015/16	27.5	18.9	9.9	10.6	19.9	27.9	30.0	5.4	17.8	11.5			
SMOK001: record of smoking status in last 24 months (15+ y), den. incl. exc. - retired	2013/14	85.6	98.9	99.7	98.8	99.2	99.4	99.8	98.7	100	99.9			
SMOK002: status recorded in last 12 mths (certain conditions), den.incl.exc.	2015/16	94.2	95.7	99.4	96.5	94.8	98.4	97.7	97.1	98.7	96.9			
SMOK004: record of offer of support and treatment (15+, last 24 mnths), den. incl. exc.	2015/16	87.0	89.9	94.7	94.8	92.8	91.5	89.6	94.6	95.9	95.9			
SMOK005: cessation support and treatment offered (certain conditions), den. incl. exc.	2015/16	94.3	94.3	94.8	88.5	99.1	98.2	95.2	98.2	96.1	97.3			
HYP008: Blood pressure <= 150/90 mmHg in people with hypertension	2015/16	79.6	79.1	76.1	75.4	81.7	89.8	81.1	89.3	67.9	86.4			
HYP003: Last (9mnths) blood pressure <= 140/90 mmHg (age <80) (den.incl.exc.) - retired	2013/14	70.4	93.2	95.9	91.4	95.5	96.1	95.7	86.6	85.8	94.4			
HYP004: Phys. act. assessment (last 12 mnths), patients with hypertension aged 16-74 (den.incl.exc.) - retired	2013/14	76.0	95.9	99.2	97.0	96.6	98.4	98.7	94.1	93.2	98.4			
HYP005: Patients w. hypertension who had a phys. act. assessment and where found to be inactive who had also a brief intervention (both in last 12mnths, aged 16-74) (den.incl.exc.) - retired	2013/14	86.3	94.3	99.1	82.9	98.7	100	98.5	100	98.4	98.7			
BP002: Patients, aged 45+, who have a record of blood pressure (last 5yrs)	2015/16	90.6	92.6	97.6	93.1	93.0	93.5	92.5	90.1	91.0	97.2			
CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins (den.incl.exc.)	2015/16	66.5	69.5	100	50.0	50.0	100	100	100	50.0	50.0			
CVD-PP002: Lifestyle advice for patients with hypertension (den. incl. exc.) - retired	2013/14	79.0	92.4	97.7	92.3	93.3	92.3	87.3	85.1	93.9	94.4			

Figure 26: ‘CVD-Risk Factors for CVD’ QOF outcomes data (Public Health England, 2016)

Returning to the example of Mrs Smith (EX34) helps to illustrate how exception reporting works. If Mrs Smith decides to pursue lifestyle change as a long-term solution to her health problems (and turn down hypertensive medications), Dr Smart will need to code her electronic record as either 'patient unsuitable' or 'informed dissent' (NHS Digital, 2016c; Primary Care Commissioning, 2014). Both of these codes remove Mrs Smith from indicator HYP006's denominator figure, which is used to calculate the percentage achievement for the QOF target. This helps to ensure that her decision does not affect her health centre's ability to hit the target percentage of patients achieving a target blood pressure of <150/90. She is 'excluded' or 'excepted' from this indicator, whilst remaining on the register (and therefore continuing to be eligible for monitoring).

Dr Smart highlights however that exception-reporting is viewed by managers with suspicion, and a high level of exception-coding (as well as other QOF indicators which vary from other local performance) is a trigger indicating that the health centre is an 'outlier'.

Nationally, they look at exception coded figures for practices and they look for practices that use high numbers of exception reporting or high percentages of exception reporting. The implication is that if you use it too much, that you'll have the CCG, or even worse, the NHS Secret Police Fraud Squad (I can't remember what they're called), [...] or the CQC, start coming to see you and say, 'Hmm, yes. You're an outlier in your CCG. You exception-code ten per cent of patients. The CCG average is five. Can you explain why that is?' Only they don't kind of put it like that. They say, 'This isn't good enough. You're gaming, you're manipulating the system.'

EX41 Dr Smart

Dr Smart tells me that being an 'outlier' flags to organisations with a governance role that his health centre should be investigated as potentially providing a poor quality of care. He mentions three organisations: the CCG; NHS Protect (the "Secret Police Fraud Squad"; and the Care Quality Commission. (This is not an exclusive list but Dr Smart's awareness of these regulatory/provider agencies underscores his knowledge that QOF outcomes are visible from a distance and that he and his colleagues are accountable for them.) Dr Smart worries that a

monitoring organisation (especially the CCG) may point to his health centre's QOF outcomes and say, "you exception-code 10% of patients", "this isn't good enough, you're gaming the system". He anticipates that the CCG will interpret a high exception-rate as evidence that they are covering up poor or inefficient practice.¹⁴⁹ As Dr Smart points out, a high exception-rate will draw attention to his health centre's practices and lead to stressful scrutiny. It is therefore important to him that he monitors exception-coding (ensuring that patients are only excluded from indicators if they threaten QOF performance).¹⁵⁰ This work to monitor and tweak records in order to ensure that the health centre does not appear as an outlier in performance metrics, is important both for the financial security of the health centre, and to facilitate efforts to practise their 'maverick' brand of 'patient-centeredness'.

As well as trying to avoid being an 'outlier', Dr Smart also has to ensure that, if his health centre *does* come under scrutiny for this, or any other reason (such as a complaint or litigation), he can demonstrate that the GP involved in the decision has acted according to expectations of good clinical practice. QOF metrics are linked to medico-legal aspects of ruling relations:

So the concern would be we didn't treat [a patient's] cholesterol down below five as per the QOF. They had a heart attack. They sued to say - the way it often happens is there's a smart doctor at the hospital who said, 'Well how come your GP hasn't given you a statin because your cholesterol was six?' Then all of a sudden that turns into a complaint or litigation.

EX42 Dr Smart

¹⁴⁹ This is sometimes called 'gaming' — understood to be when health centres "use exception reporting at the end of the payment year to help them meet unmet targets" — "to maximise income at the expense of patient care" (Roland, 2015).

¹⁵⁰ For instance, if a patient's blood pressure reading reduces to below the target measurement (HYP006), an exception-code is not required in order to meet the target, even if they have declined medications. Additionally, as indicators do not require 100% compliance in order to achieve the maximum number of points, a limited number of patient records could be 'non-compliant' without the requirement to exempt from the indicator.

Dr Smart understands that QOF metrics show the *quality of care* his health centre provides in the eyes of local policymakers. He needs to be able to demonstrate that Mrs Smith, for instance, has been exception-coded based on *sound clinical grounds* (e.g. not tolerating medications), or that she has communicated her own *preference* to ‘dissent’ based on an ‘*informed decision*’ in order to justify treatment which is outside of guideline recommendations. This explains the way in which GPs carefully document decisions in patients’ electronic record, an activity which is made critically important when the clinical decision is contrary to the guideline’s recommendation (see Chapter 7). In health centres where GPs actively facilitate ‘dissent’ (i.e. they encourage a “meaningful conversation” about a “spectrum of options” including declining medications (EX34)), the work involved in managing the QOF reporting system may be particularly challenging.

8.6 Aligning incentives to increase the prevalence of risk conditions

The QOF targets highlighted so far in this chapter orientate HCPs’ work towards ensuring that patients who are *already diagnosed* with a risk condition are *treated*. In the remainder of this chapter, I turn my attention to QOF targets which draw their work into *finding people* within the population with *unidentified risk conditions* — and ensuring that they are textually categorised within health centre records using *diagnostic codes*.

As highlighted in 2.4, increasing the ‘observed prevalence’ of risk conditions (i.e. the proportion of patients within a health centre’s registered population who have been identified with that risk condition) is a major priority for policymakers. Within the logic of GBD discourse, it is assumed that the ‘*true*’ *prevalence* of risk conditions within a population will always be *higher* than the ‘*observed*’ *prevalence as captured through the QOF system*. An example of one health centre’s ‘area profile’ (which includes prevalence rates for various risk factors and conditions) is shown at Figure 27. A higher prevalence of risk conditions is usually understood to indicate that the health centre is better performing — a low prevalence rate textually highlights that a health centre is not effective at picking up new cases.

Chapter 8 Facilitating meaningful conversations

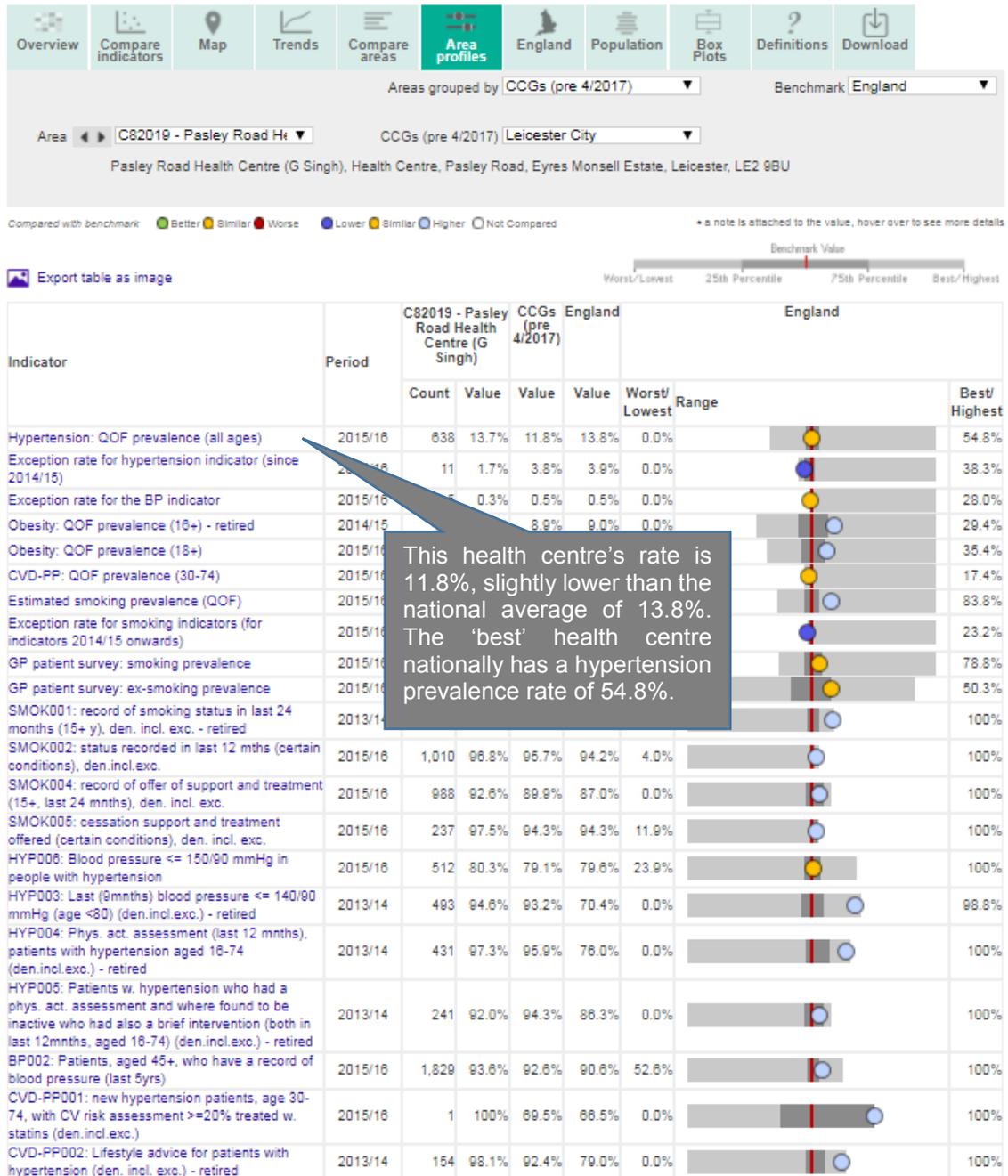


Figure 27: Area profile for health centre C82019 ('CVD-Risk factors for CVD' domain)

Even more important within this schema is the 'prevalence ratio' which more specifically indicates to policymakers how well health centres (and regions overall) are addressing the 'prevalence gap' between observed and estimated prevalence (see 2.5, p.36). The lower the ratio, the better the performance is deemed to be (see Figure 28).

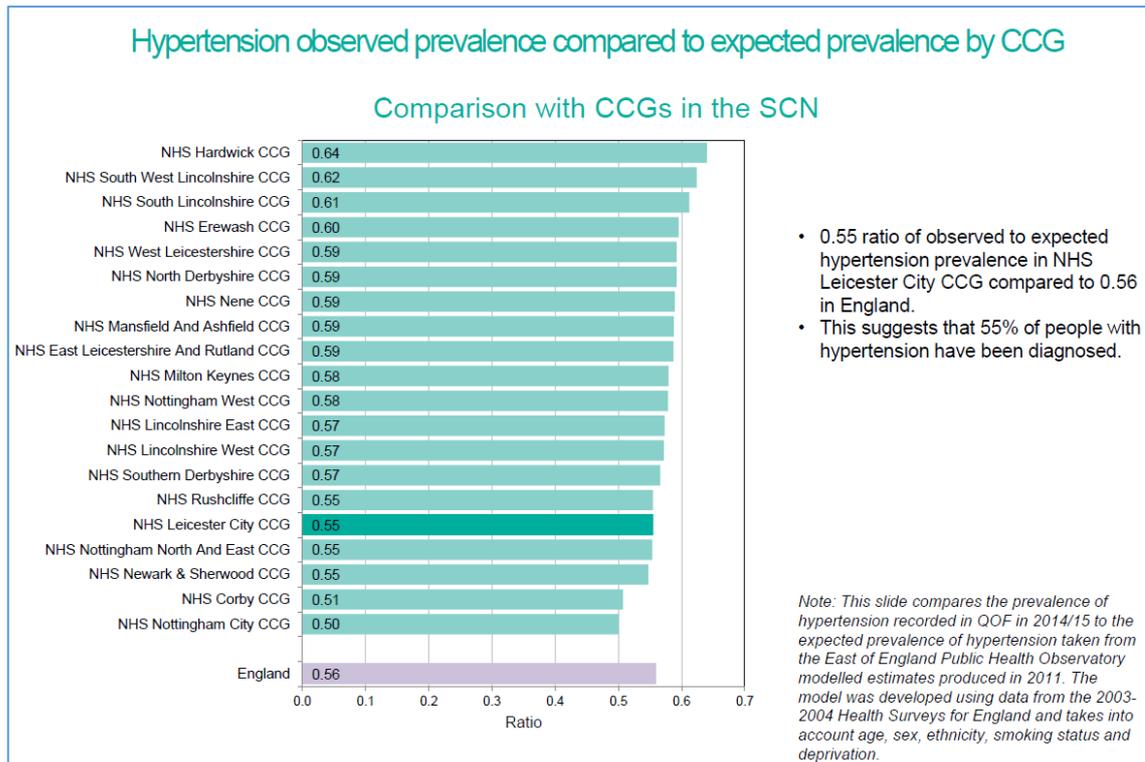


Figure 28: Ratios of observed (QOF) to estimated prevalence of hypertension by CCG area (CVD Primary Care Intelligence Pack (Public Health England, 2016b))¹⁵¹

QOF prevalence targets institutionally re-orientate health centre managers’ (and HCPs’) work away from being ‘illness’ focused, and towards being ‘prevention’ or ‘health’ focused — i.e. it benefits health centres financially and reputationally to systematically look for unidentified risk conditions within the population.¹⁵²

8.6.1 Aligning the Health Check with the QOF

Architects of the national Health Check programme have aligned the programme to feed patients into the QOF incentive system — see the Health Check programme’s ‘Making the Case’ webpage (NHS Health Check, 2016b). CCG and local authority objectives too are textually aligned to the ambition of improving prevalence metrics. Key to English-town’s Health and Wellbeing Strategy is identifying new cases of disease through the Health Check programme (see

¹⁵¹ This graph shows (as an example) prevalence data for Leicester City CCG in which the University of Leicester is situated.

¹⁵² The QOF funding formulae for incentivising disease prevalence are complex. Although health centres receive QOF points for ‘maintaining a register’, their final funding allocation is calibrated to be greater the more people they have on that register.

Humphries and Galea, 2013). In order to ensure that the Health Check programme is effective at increasing prevalence metrics, policymakers in English-town undertake significant work to ensure that local funding flows are aligned. Dr Sully refers to the importance of the way that English-town has structured the payment system for the Health Check programme:

One of the reasons it's worked well is the way GPs and practices are reimbursed for their time, so they get paid to do the Part1, they get paid to do the Part2, so there's extra reimbursement coming, so they can actually release resources to actually make this thing work.

EX43 Dr Sully

Health centres are paid by the local authority to deliver the Health Check programme. It is funded through the 'Public Health pot' as opposed to the core GP contract for provision of general medical services (2.6), and is therefore helpful additional income for health centres — a “revenue generator” as Sergei (from the local CCG) described it. However, in practice it nevertheless takes away from HCPs' time for routine practice. As Dr Sully points out, in order to “make [the Health Check] work”, health centres need to “release resources” — presumably in some cases by prioritising the Health Check over the care of patients with established conditions (in the context of heavy GP workloads and recruitment problems).

The structure of the Health Check payment system into two 'parts' ensures that health centres fully invest resources into the programme, delivering all the aspects of the check which are important within the visible performance monitoring of the local Health Check programme.¹⁵³ Alan and Dr Sully, both involved in the local management of the programme, told me this had “streamlined the process”; by this, they mean that the structure of the contract financially incentivises the health centres within their jurisdictional oversight to

¹⁵³ As I have previously shown, it would be easy for HCPs to omit diagnosis and treatment of risk / risk conditions (the main visible measures of the programme), as these usually happen after the patient has left the Part 1 appointment.

complete Part 2 (which otherwise might be overlooked) as well as Part 1 of the check. Local policymakers understand this to be important in order to ensure that patients are screened and, wherever applicable, also *diagnosed*. This will push prevalence rates up and, in turn, will also demonstrate that the health centre is undertaking the work required to then tackle the ‘burden of disease’ through *treating* high-risk or a risk condition.

HCPs’ work at Part 2 of the Health Check is highly coordinated by the *textual positioning of a decision about medications*. By incentivising the Part 2 consultation, *an offer of treatment is assured* (see 7.2). Although many HCPs may be unconvinced of the benefits of particular medications for an individual patient, the positioning of this ‘offer’, combined with the time-limitations of the consultation, organises them to promote the benefits of these medications (as evidence-based, guideline-recommended treatments to reduce risk). As I showed in Chapter 7, by activating ideas about EBM and ‘following guidelines’ they are able to avoid extensive discussion of the uncertainties surrounding preventive medications such as statins (4.4.1 and 7.4). HCPs therefore tend to promote statins, even when not incentivised through the QOF, whilst emphasising that the decision is ultimately the patient’s (“it’s up to them” 7.3).¹⁵⁴

8.6.2 Local commissioners’ ‘outcomes’

I have not expanded this analysis into the complexity of CCG and local authority performance targets. However, in this section, I show that local policymakers are highly attuned to the national performance metrics to which they are accountable, and seek to ensure that the health centres under their jurisdictional oversight support this wider local performance. It was a matter of pride to Alan (who had management responsibility for the English-town Health Check programme), that English-town had achieved national recognition for its high ‘uptake’ rates (i.e. the number of Health Checks delivered). As Alan pointed out, “I’ve had places, you know, all up and down the country ring me up to say ‘oh we’ve seen [English-town’s results], what are you doing that’s different?’”. This good ‘uptake’ will

¹⁵⁴ HCPs may also have been conscious that an ambition existed (as yet unfulfilled) to incentivise statins prescribing more widely (Pulse Today, 2015a). This did not arise in discussions, but was widely known at the time of this study.

directly contribute to the broader goal of increasing prevalence. In the excerpt below, Luis (who works for the CCG) highlights the Health Check's importance in generating textual evidence of outcomes already highlighted in this chapter:

*From a CCG monitoring point of view, the main output [from the Health Check programme] is the **number of Health Checks delivered**, but it also feeds into things like concerns about **prevalence of long term conditions**. So we would be interested in the number of new patients diagnosed with diabetes for example or the number of new hypertensives identified and started on evidence based treatment. [...] If you take a single component like blood pressure checks, identifying people who are persistently hypertensive, offering them structured advice, evidence based advice, and if necessary starting medication, and sending them on for further investigations, all of that is part of a structured iterative approach in primary care to **ascertain new cases, managing them early**, and we know from a CCG point of view, that there is a relationship between managing hypertension well, finding new hypertensives, helping those patients to find the right treatment combinations, and a **reduction in terms of early mortality and morbidity** from things like stroke, MI and so forth. (Emphasis mine)*

EX44 Luis

Although the local authority outcomes recorded for the Health Check programme are very simple (number of people invited, and number of checks delivered), Luis's account reemphasises that these metrics directly link to the CCG's interest in "ascertaining new cases" and "managing them early" in order to demonstrate regional performance outcomes.

*Every CCG is constantly reviewing its numerical performance so, 'are we meeting sort of the national targets' and I imagine like a lot of other CCGs we are also critically examining what are the real [pause] **outcomes**, how we are changing population outcomes and individual outcomes. (Emphasis mine)*

EX45 Luis

Even though he was not directly responsible for reporting these performance targets, Luis was conscious of the “numerical performance” on which the CCG was judged; this permeated the work of agents at the CCG as also described by Sergei:

So Public Health England will say right well [English-town] you ought to have a 12 per cent prevalence in diabetes. Actually your QOF data shows that you're 8 per cent. You need to put more effort into identifying these patients and getting them to come forward.

EX46 Sergei

Here, Sergei explains that policymakers invest time and resources to engage health centre managers in monitoring and improving their QOF performance measures — e.g. their prevalence rates in this case. English-town, for instance, employs ‘neighbourhood’ teams to remedially intervene in the light of health centres’ performance data (interviews with Alan and Sergei). The aim of this activity, Alan volunteered, was not ‘performance management’ but to *support* health centres in maximising their income and reputation by channelling their activities more effectively towards these performance metrics:

*So we'll meet with GPs and try to understand what issues are, [...] we'll go along to locality ['neighbourhood'] meetings say 'this locality has fallen in the last two or three months'. We can speak about it in several ways. One, you know (slightly mercenary really), the slight loss of income, this is how much you would have got (and generally that obviously doesn't motivate GPs, it's more about helping patients). **What does motivate is the competitive element.** (emphasis mine)*

EX47 Alan

Local policymakers are focused on driving up local Health Check programme metrics by promoting competition, and creating uncomfortable scrutiny on ‘outlier’ health centres (8.5); this is the pressure of which Dr Smart spoke in EX39. Policymakers understand these indicators to demonstrate that the local health community (including CCG, local authority, and health centres working together)

are improving outcomes by seeking out new risk conditions in the population and treating them with medications.

8.7 Harvesting the ‘low-hanging fruit’: low cost, high dividend prevention

As I have shown, although the local authority and the CCG’s accountability systems are different to those of health centres, the ‘outcomes’ to which they work are coordinated within a unified accountability apparatus which governs preventive activities at the frontline. As discussed in Chapter 2, prevention has received increased focus over recent years as a sphere of activity which can contribute to the financial sustainability of the NHS. In England, the current (and anticipated) funding crisis, as indicated in the Five Year Forward View, has led to new programmes of work specifically designed to deliver cost savings and ‘sustainability’. Performance metrics, presented in the form of data tools/packs (from which the figures in this chapter are taken), are increasingly promoted by national policymakers, and utilised by local policymakers, to drive health and financial improvements. National policymakers aim, through such data tools, to “highlight opportunities to be more efficient, to gain greater value from constrained budgets and to improve health outcomes for patients” and also to “address gaps in prevention, treatment and care, without increasing primary care workload” (Fenton, 2016). From an economic perspective, this is activity which is expected to reduce the ‘burden of CVD’ with minimal financial expenditure, and which is calculated to generate savings in the longer term.

Central to the messaging associated with the promotion of these tools is that they will ensure a “consistent quality of care” (Fenton, 2016) — i.e. increased equality through identifying *variation* in diagnosis and treatment across the country and within local regions.¹⁵⁵ A particular focus for local policymakers is on ‘prevalence gaps’ as already shown. These gaps are institutionally important as they are understood by policymakers as “low-hanging fruit” (Kearney and Freeman, 2016) — easy pickings which (through treatment of newly identified conditions) will lead to the ‘win-win’ situation of saved lives and costs (see 2.6). These prevalence

¹⁵⁵ Kevin Fenton is Public Health England National Director for Health and Wellbeing.

data feed into the bigger narratives (knowledge / facts) about ‘opportunities’ within the local area to reduce the burden of disease and organise local policymakers to invest their resources in this fruitful ‘harvesting’ work. Additional tools such as the Health Check ‘Ready Reckoner’ and the ‘Size of the Prize’ resources (NHS Health Check, 2017) (see also 2.5) provide additional tools whereby healthcare commissioners can tie the estimated health outcomes from treating risk conditions to projections about savings from these new diagnoses (The UK’s Faculty of Public Health, 2017), and prioritise their improvement activity. The prevalence gap for hypertension, atrial fibrillation, high CVD risk / cholesterol, diabetes, prediabetes and chronic kidney disease have become particular targets for attention, as these are all thought to be considerably under-diagnosed, based on modelling (Kearney and Freeman, 2016).

Embedded in the data packs utilised by local policymakers are the management technologies of ‘variation modelling’ and ‘benchmarking’ which are integral to “[improving] the value and utilisation of resources” (Public Health England and NHS RightCare, 2016). These technologies were prominent in presentations by national CVD leaders at a conference I attended in 2016,¹⁵⁶ and drive the local accountability systems governing health centres’ practices. The use of such management technologies has already been highlighted in this chapter: in Figure 27 health centres are compared with best performers and national averages (benchmarking); and Figure 28 shows variation in prevalence of hypertension (variation modelling).¹⁵⁷ Identifying ‘low hanging fruit’ is a *comparative* work which, using variation modelling and benchmarking, draws multiple actors into increasingly targeted activities, and privileges a form of knowledge about preventing CVD focused almost exclusively on diagnosing and treating targeted risk conditions. Within this institutional frame, commissioners and policymakers understand health centres with high prevalence ratios as delivering poor quality

¹⁵⁶ For details, see the conference website (Issues & Answers in Cardiovascular Disease, 2018).

¹⁵⁷ Drawing on Wennberg’s (2011) work on ‘unwarranted variation’ and the ‘Atlas of Variation’, the authors of the CVD Intelligence Packs argue that the variation between regions, as seen in Figure 28, is likely not to be explained “on the basis of illness, medical evidence, or patient preference” but is instead likely to be due to “the willingness and ability of doctors to offer treatment” (Public Health England, 2016b). They suggest that these data demonstrate the complacency of frontline HCPs and local healthcare managers.

care to patients; patients who are not diagnosed and treated are viewed to be receiving substandard healthcare. Reducing the ‘prevalence gap’ is often rhetorically linked to other ‘gaps’ which emphasise this metric’s importance within wider understandings of healthcare provision — e.g. to a “productivity gap” (NHS RightCare, 2015) (thus linking it with cost-saving), and with a “wellbeing” or “quality” gap (Kearney and Freeman, 2016), (creating the illusion that such GBD-orientated work is attending more broadly to the general health of individual patients).

8.8 Summary

In this chapter, I showed that authoritative knowledge about population health, derived originally from clinical practice datasets, is textually produced as performance metrics relating to the diagnosis and treatment of risk conditions — by which local policymakers monitor and incentivise particular frontline activities within health centres. This authoritative knowledge about prevention, and the practices associated with it, coordinate many of the tensions in frontline HCPs practices that have been described in chapters 5, 6, 7, and in this chapter. Here, I particularly focused on the work of activist GPs (mostly managing partners) who are attempting to provide ‘patient-led’ care — to facilitate ‘meaningful conversations’ with their patients, and to support them with knowing how they can best improve their overall health — to incorporate the type of care practices which I have shown previously to be organised out of the ruling structures of preventive care. I showed how even these activist GPs’ work is coordinated in relation to performance metrics about disease prevalence and treatment of particular risk conditions; these GP partners find it difficult to practise in the manner to which they aspire and engage in particularly challenging work to ensure that they are not perceived as ‘outliers’, and avoid forfeiting indispensable income. Perhaps more fundamentally, I also have shown some of the emotional, mental labour of figuring out how to practise differently and present those differences to others.

Chapter 9 Mapping prevention's accountability circuit

I started this thesis with the apparently self-evident maxim, 'prevention is better than cure'. In common parlance, prevention is indeed better than cure because "it saves the labour of being sick" (Adams, 1618). However, my exploration of prevention practices has uncovered many instances where patients experience difficulties with 'fitting' prevention work into their everyday lives. These patients are drawn into considerable 'labour' of prevention (or 'work' to use IE's term). Their work not only involves the inevitable troublesomeness of following advice to change lifestyle or take medications, but points to more fundamental clashes between the social organisation of 'preventive care' and patients' (and some HCPs') more local and embodied understandings of 'care'. In Chapter 1, I introduced Dan, who told me that he had been unable to have a "meaningful conversation" with his GP (EX1). In chapter 5, I used the example of Naomi who also hoped for a 'conversation' with her GP about the broad set of problems affecting her health, but who found that institutional processes did not facilitate this (EX5). These problems are reflected in Dr Smart's comment that it is difficult for him to find time to have "meaningful conversations" with his patients, and especially then to ensure that their preferences are "implemented" (EX37 / EX32). Although I have highlighted Naomi's situation as particularly challenging, many other patients also experienced tensions as preventive care entered into their everyday lives, and struggled to communicate with HCPs about how prevention work did, or did not, 'fit' (see Chapter 1). Dan's experiences, and the experiences of other patients encountered in this thesis, although different from Naomi's in many ways, are similar in this regard. Expanding on Mol's (2008) compelling vision of the 'logic of care' (see 3.3.2), I asked the question, "*how* is it that patients' appeals for care frequently go unheard within the social organisation of preventive care?" (5.8). This question encapsulated the problematic guiding my analysis.

In order to answer this question, and to draw together the analysis already presented, I use Smith's concept of 'accountability circuits'. I show that the coordinated practices of prevention's accountability circuit, built on abstract metrics orientated to reducing an ideological construction of 'burden of disease' (Chapter 2), are implicated in the serious (and various) troubles for patients and

HCPs that I have shown throughout this thesis (people and their work who are the objects of ideological practices). Authoritative textual representations of population prevention work make individuals' bodies institutionally 'actionable' but in ways which create significant tensions in their lives. In particular, the accountability circuit (and its metrics) organise the fragmentation of preventive support which I have shown is difficult for patients to navigate.

I then return to a discussion of what is important to patients, and of the work into which patients are drawn as part of the preventive practices. In contrast to the dominant conception that frontline HCPs harmoniously work with patients to manage their preventive needs, I highlight that patients frequently resort to managing their preventive activities themselves, utilising their own network of resources when HCPs appear unwilling or unable to respond to their individual needs or preferences in the ways they would find most helpful. Patients may find themselves having to actively manage their interactions with HCPs who are offering 'preventive care', in an attempt to negotiate a practical "compromise between different 'goods'" (Mol et al., 2010, p.13) (3.3.2) — or at least to ensure that these relationships are not permanently fractured. On the other hand, if HCPs want to support patients to find preventive solutions which fit with their lives and priorities, they may have to overcome accusations of 'paternalism'.

I highlight that, although performance metrics are highly visible within *policymaking* arenas, they blur into the background in *clinical practice/academic* arenas. Ideological practices of knowing about Health Checks, risk scores, interventions and 'prevention' obscure the tensions embedded in the ruling relations of the accountability circuits, and gloss over a great deal of what is actually happening in clinical consultations. Frontline HCPs become confident in their knowledge that 'this is how it works'. Finally, I summarise this study's contribution to knowledge about CVD prevention, and reflect on the IE approach taken.

9.1 Accountability circuits

I have previously outlined the IE concept of 'ideology' as abstracted knowledge carrying authority (3.2). This knowledge is activated in people's *practices*, which are coordinated by texts in sequences of action (Figure 15). Sequences of action

become circular when multiple texts are configured in an '**intertextual hierarchy**' (Smith, 2006b, p.79). A regulatory text (or '**boss text**') (which is usually not visible in the *local* setting) regulates and standardises other texts (those which enter into local practices). It does this not by "prescribing action" (as if the text holds innate power), but by "establishing the concepts and categories, in terms of which *what is done* can be recognised as an instance or expression of the textually authorised procedure" (Smith, 2006b, p.83) (emphasis mine). The work of producing subordinate texts becomes circular as people work to activate the concepts of the regulatory text in the subordinate text, and then 'circle back' to ensure that this subordinate text fits with the regulatory text (see *ibid.*, p.85 for more detail). Smith writes that "the circularity of intertextual hierarchies is integral to the organisation of the contemporary ruling relations in general, including large-scale organisations and those functional complexes we have called *institutions*" (*ibid.*, p.85-86). It is the subordinate texts which directly enter into frontline work in local settings that organise what happens there. As I have shown, the frontline practices of CVD prevention are replete with these texts — and, in addition, knowledge (ideologies) from multiple texts is often grouped as a single 'text' as is the case in a clinical guideline such as CG181 — as part of an "intertextual complex" or "hierarchy" (Rankin and Campbell, 2006, p.121; Smith, 2006b, p.66). A guideline text such as CG181 is produced from multiple 'regulatory texts' — for example, which are used to determine processes for diagnosis, or outline the principles of good 'patient experience'.

Developed from the ideas above, IE's conceptual framework for identifying, describing and explicating '**ACCOUNTABILITY CIRCUITS**', is used here to draw together the findings of this study. The notion of accountability circuits is allied with Smith's earlier conception of ideology and 'ideological circles' (Griffith and Smith, 2014b)¹⁵⁸ — it draws on, and expands, the ideas of textual coordination outlined above. Accountability circuits are considered to be a particular feature embedded in the introduction of neoliberal market-based models into frontline

¹⁵⁸ There are subtle differences in the way that these circular representations are used in IE, but it is not important to distinguish between them here.

public sector organisations. Griffith and Smith (ibid., p.10). describe them in the following way:

“Institutional circuits [of which ‘accountability circuits are a ‘subcategory’] are recognisable and traceable sequences of institutional action in which work is done to produce texts that select from actualities to build textual representations fitting an authoritative or ‘boss text’ in such a way that an institutional course of action can follow. Once a textual representation fitting the categories / concepts established by the authorised or boss text has been produced, the actuality (as textually represented) becomes institutionally actionable.”

‘Accountability circuits’ very specifically “aim to produce frontline accountability” by bringing people’s frontline work “into alignment with institutional imperatives through the activation of texts” (2014c, p.14) — in the case of CVD prevention, people are actively at work to textually represent people (or their actions) as requiring intervention.

9.2 The coordinated practices of CVD prevention: an accountability circuit

Based on the data presented in this study, I have sketched a simplified schema of the complex accountability circuit for CVD prevention at Figure 29.¹⁵⁹ It provides an overview of how the coordinated set of practices known as ‘CVD prevention’ (the subject of this thesis) are put together and are orientated towards demonstrating impact on textual (conceptualised) constructions of the ‘burden of disease’ (Chapter 2).

¹⁵⁹ I have based this representation on Smith’s (1983) diagram of an ‘ideological circle’. It is inverted to also reflect her “small hero” diagram (Smith, 2006a, p.3) in which she also uses the metaphor of an individual ‘looking up’ or ‘shining a light’ into the ruling relations organising their everyday work.

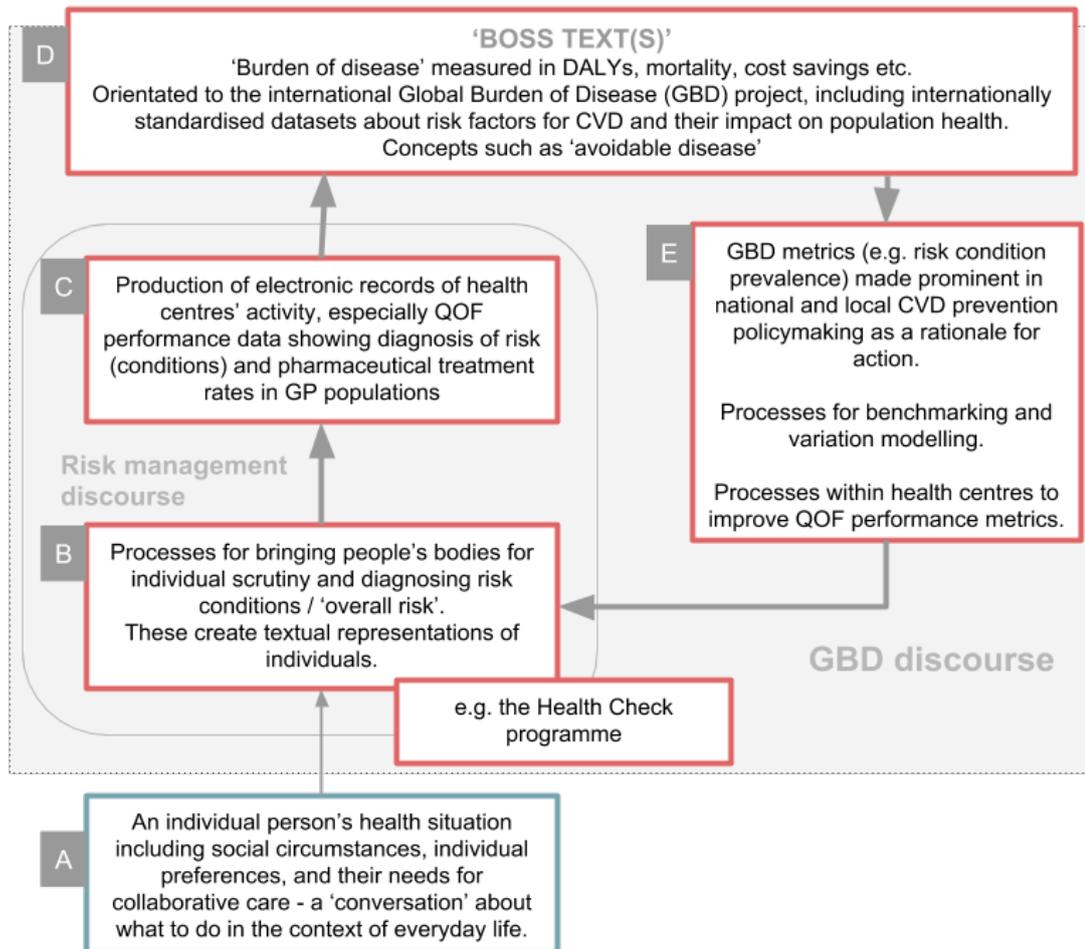


Figure 29: CVD prevention — an accountability circuit

This diagram shows where this study's exploration (the "thread through the maze") led (Smith, 2005b, p.54). It supports the explication of the problematic, put together over the previous chapters. Of course, it does not include all of the complexities involved in the coordinated practices of CVD prevention. However, it shows the major textual processes which are dominant organisers of HCPs' and patients' work, and how this is orientated to constructions of global 'burden of disease' (GBD). Specifically, it shows how an individual's life and health needs [A] are textually **and selectively** 'worked up' through a 'diagnosis of risk' [B], and the production of records (mainly through the QOF) which demonstrate successful 'prevention' through metrics related to diagnosis and treatment of particular risk conditions [C]. These records are organised within the GBD discourse outlined in Chapter 2, and feed into a standardised textual representation of the 'burden of disease' in a population — the '**boss text**' [D]. As discussed in 2.2, although GBD is technically a measurement of Disability

Adjusted Life Years (DALYs), it is an epidemiological concept that may also be activated using related statistics of 'mortality', 'prevalence', or even cost savings. The sequence of action does not end there however, but becomes circular when national and then local policymakers activate GBD metrics from international GBD work, in order to drive improvements in general practice [E]. These 'improvements' focus (again *selectively*) on renewing efforts to increase diagnosis and treatment [B/C] — within the textual processes privileged by the accountability circuit. The circuit generates the practices of healthcare services administrators *and* frontline professionals whose work is not only to improve the 'health' of the population, but also to produce economic savings which are expected to make the current forms of health services sustainable. The Health Check programme, which has been a major focus of this study (and is a flagship programme for CVD prevention) funnels individuals into the accountability circuit by bringing them under the scrutiny of the health centre and enabling the application of prevention's various diagnostic technologies (Chapter 6). In particular, risk scoring technology (which is embedded into the Health Check's textual sequence) provides a new 'diagnostic' route whereby patients may be determined to be 'at risk' and require treatment (Chapter 7). In the following sections, I fill out the diagrammatic representation of prevention's accountability circuit as a way of summarising some of the main findings of this study. First (in 9.3 below) I show how the accountability circuit operates with particular reference to Naomi's account.

9.3 Illustrating the accountability circuit through Naomi's account

Here, I specifically highlight how the circuit's accountability practices organise Naomi's experience (Chapter 5). Naomi has numerous problems which relate to her ability to initiate and sustain healthy lifestyle habits. However, her situation is textually represented at her health centre, and within healthcare records, as a set of risk condition diagnoses such as hypertension and obesity. Naomi's GP is focused on managing these risk conditions with 'evidence based interventions', which she understands will reduce Naomi's risk. Diagnoses and treatments which are understood to be particularly institutionally important are recorded and incentivised through the QOF system. Naomi's GP is therefore orientated

towards bringing her hypertension to target levels despite Naomi's appeals for a broader conversation about her health and protestations that the medications give her headaches. Simultaneously, the GP reiterates to Naomi that she needs to lose weight and that her 'other problems' (such as cellulitis, gout etc.) are the consequences of her weight. However, the significant and difficult changes which would be required for Naomi to lose weight are organised out of the GP's purview, and Naomi is offered little tangible support to enable her to improve her current physical condition within the complexities of her everyday life.

The sequence of action shown in Figure 29 orientates HCPs' work to produce textual representations of how Naomi's CVD risk is being 'prevented'. Health centres are accountable for preventive 'outcomes' recorded through the Quality and Outcomes Framework (QOF). As I have shown, these prioritise pharmaceutical treatment of risk conditions over (for instance) 'lifestyle' interventions or other potential support. Treatment of Naomi's hypertension is not only incentivised, but simultaneously demonstrates (textually) to local and national policymakers that healthcare services are successfully 'preventing' CVD i.e. reducing the burden of disease. In order to promote such preventive work, local policymakers use a range of metrics to drive improvements in the health centre's performance. The GP partners at Naomi's health centre can avoid uncomfortable scrutiny if they can demonstrate through these metrics that the health centre is identifying and treating risk conditions, and thereby contributing to reducing the burden of disease. Each person who is textually represented as being treated contributes to a 'prize' for local policymakers in terms of the production of metrics representing lives and costs saved.

Naomi's weight (and the social circumstances which contribute to it) have some relevance within this accountability circuit — the health centre is rewarded for keeping a register of people who are 'obese' (above a particular BMI threshold) — but there is (at present) no incentive within the circuit's formulation for HCPs to proactively support her to lose weight. In addition, HCPs know that trying to offer truly engaged and useful support to Naomi may involve 'opening a can of worms' which they do not have the time or expertise to address (How can her GP help her with the housing problem which is dominating her thoughts, for instance?) Naomi therefore has scant hope of losing weight. The 'support'

provided for her to undertake this work is limited to (for example) diet sheets or standardised lifestyle interventions (Chapter 4) which offer little opportunity for 'conversation' about *realistic* approaches to make the small steps that would be necessary to improve her health, or provide ongoing support to review and adapt 'prevention' to her circumstances. Opportunities to "tinker with bodies, technologies and knowledge" in order to work out "local solutions to specific problems" (Mol, 2008, p.14; Mol et al., 2010, pp.13–14) are not part of the current social organisation of healthcare. The findings of this study indicate that, although GPs may sometimes attempt to 'make time' by altering their appointment schedules, or by arranging for patients like Naomi to have more extended discussions with a nurse, this is difficult to accommodate within the operation of prevention's accountability circuit (itself operating within the broader pressures of general practice).

9.4 What's wrong with metrics?

Metrics relating to the prevalence and treatment of risk conditions (e.g. QOF metrics), as I showed in Chapter 8, are foundational to national policymakers' knowledge of population health needs — the burden of disease. Burden of disease (and its variants as above) act as 'boss texts' (Smith and Turner, 2014, p.10), according to which these other textual representations are interpreted. As a result, metrics, such as those included in the QOF, become increasingly "articulated to an institutionally mandated course of action" (ibid.) as policymakers use them to stimulate improvement work. Subsequently, improvement work is internally validated (within the circuit) *by* improved metrics. At a population level, good metrics allow local policymakers to gauge their 'success' in comparison to other regions (for example, by showing how they are reducing the 'burden of CVD' and consequently claiming the 'prizes' in terms of lives and costs saved (2.5). Utilising the same set of management technologies as those at national level (i.e. variation modelling, benchmarking), local policymakers scrutinise metrics at the level of frontline practice. Health centres are rated against each other, 'outliers' picked out for attention, and then spurred into action. Policymakers are continually trying to improve the granularity of the data collected from general practice databases so that they can guide preventive interventions towards small, localised 'targets' which have been identified as particularly

desirable 'prizes'. This accountability circuit of prevention is organised to keep spiralling round, creating 'whirlpool-like' courses of action as the activities of HCPs and patients are tightly orientated to its coordinating texts.

The science behind calculations of (global) 'burden of disease' has undoubtedly been a huge achievement, providing knowledge of populations which had previously not been possible. My argument is not that the accountability circuit, or GBD metrics are in themselves *'bad'*, but that they powerfully coordinate people's activities, their energies and consciousness (from policymaking to the frontline) in ways which frequently exclude HCPs' capacity to see what is happening and respond to the subjectivities of actual patients — to 'care'. The analysis presented in this thesis shows that work which does not directly contribute to prevention's accountability structures is frequently excluded, or relegated to superficial ephemera. Even though HCPs may be 'encouraged' to undertake such work through the stylistic language in policy texts and guidelines, (and these ideas may resonate with HCPs' own motivations and ethics), there are multiple barriers to incorporating care practices. The support which is most likely to help Naomi with taking her first small steps to improving her health (e.g. the 'conversation' she wants to have with an HCP about the broad range of issues affecting her health) *does not directly contribute to the textual representations through which this accountability circuit is connected*, and therefore has little institutional relevance (HCPs are organised to actively disengage from patients' 'social problems' — see Chapter 6). This care is excluded *despite* ideas about 'patient-centred care' and supporting lifestyle change circulating widely and having rhetorical prominence in prevention policy (Pedersen et al., 2013; Tomlinson, 2014).

Alongside this exclusion of individualised and adaptive 'care' practices, the accountability circuit, and the metrics inherent to it, have the potential to create false confidence amongst those engaged in working towards the goals constructed in the circuit. Policymakers, managers and HCPs may confidently assume that metrics accurately reflect a 'reality on the ground'. They may also assume that doggedly focusing their attentions on metrics (e.g. increasing the 'observed prevalence' of risk conditions (as measured through data submitted to claim QOF incentives)) will unfailingly improve population health. It has been

beyond the scope of this thesis to adjudicate on the controversies around the science of CVD prevention, but it is clear that multiple uncertainties and controversies remain which suggest this confidence may be misplaced.

'Metrics' however should not be isolated as troublesome in themselves. This thesis has focused on how these are activated *in practice*, by policymakers (managers) working outside frontline clinical practice, who are motivated by regional and national competition affecting their status and personal career aspirations. I have shown how in turn metrics organise the local practices of frontline HCPs and patients by mapping an accountability circuit which explicates Naomi's unique set of experiences, and also the broader problematic of this study. Empirical analysis of junctures of the accountability circuit helps to answer the question "how is it that patients' appeals for 'care' frequently go unheard within the social organisation of preventive care?" The account I have built using the IE method of inquiry provides an alternative explication to the conclusions drawn by Dan and Julia (1.2) who suggested, for instance, that HCPs want to assert their importance, are badly trained, or are receiving bonuses from a pharmaceutical company. The accountability circuit outlined here is not a complete or final answer to the questions posed by the problematic, but it does provide an important institutional analysis which has not previously been explicated — at least not using this ontological approach with its emphasis on texts and people's practices. The research findings might point patients like Dan and Julia to the social organisation of their HCPs' work, to the accountability structures through which this work is managed, and consequently to the ways in which their own experiences of preventive care are organised.

9.5 Extending an examination of accountability practices

In presenting the accountability circuit in Figure 29, it is important to note that my empirical analysis started locally — with individuals' health needs [A]. I have shown through detailed analysis of frontline practices how patients' individual health needs are represented textually and how performance metrics contribute to policymakers' knowledge about the 'burden of disease' in the population. My analytical approach has involved following threads inductively from standpoint informant accounts, into frontline practices, and further into local and national policymaking. Partly as a consequence of this empirical, inductive approach, the

connections I show here become more opaque as I move away from frontline practices and into the institutional structures organising them (i.e. between boxes [C], [D], and [E]). I have not, for instance, conducted detailed analyses of the multiple textual practices by which policymakers utilise, and connect, general practice datasets such as QOF, national performance metrics, and the GBD project. This analysis is therefore inevitably limited in its scope compared with the detailed analyses of local prevention practices on which chapters 5-8 are based.¹⁶⁰ My data suggest that such connections are also the subject of 'improvement' work — for instance, moves are afoot to tighten the data collection practices in which general practice and policymakers are involved (e.g. NHS Health Check, 2016c, 2016b). These ongoing institutional practices could be the subject of another study (see below). Nonetheless, through the (often laborious) process of following clues within policy and other materials (e.g. online blogs, social media, conferences), I have empirically amassed evidence to describe the important textual connections through which people's work is organised.

Much more could be added to the account (and the accountability practices) that I have presented in this thesis. Indeed, the accounts of other informants pointed me to many aspects of the social organisation of prevention to which I have only gestured here. The pharmaceutical industry, as referenced by Dan, is strongly implicated — although it no longer focuses its activities at the level of health centres.¹⁶¹ Informants involved in the processes of assimilating and disseminating research evidence highlighted the textual processes, and the accompanying wrangling, which takes place over how evidence should be understood and presented; it is clear that institutional practices involving the pharmaceutical industry actively shape the work of those producing epidemiological, and interventional, research evidence. Such practices, orientated towards pharmaceutical company commercial interests, occur 'high

¹⁶⁰ I have not analysed the practices by which national policymakers textually coordinate English datasets with international GBD calculations through the GBD project. It should be noted that QOF is not a direct data source for GBD analyses (for lists of data sources, see, for example, Newton et al., 2015) but is widely used by local and national policymakers to demonstrate that they are reducing the 'burden of disease' (see Chapter 8).

¹⁶¹ The practices by which HCPs received overt incentives from pharmaceutical companies have mostly been outlawed in the UK.

up' in the institutional complex highlighted here — and involve researchers, journal editors, and so on. Informants in this study¹⁶², for instance, reported that within guideline development groups, there was frequently acrimony over how complex (and often debatable) evidence should be communicated as clear recommendations for practice (see 3.1 / 4.4), and that GP and lay members presenting their frontline knowledge of what is important to patients in preventive care were liable to be overruled by specialists. One informant talked about the “vested interests” of specialist members of the guideline development group of which he had also been a member — in terms of both academic status and indirect links to pharmaceutical industry funding. This, he proposed, led them to lobby for particularly medication-orientated recommendations such as ‘treatment-to-target’ (an approach which involves increasing medications until a target level is achieved). However, this is another story, on which it is not possible to elaborate here, but which would illuminate and add detail to the accountability practices presented. The discursive organisation of epidemiological and interventional research funding, payments for conference presentations, guideline development processes, and other related activities would be useful domains for further IE analysis.

9.6 Interventions and automatons: fragmentation of preventive support

An important aspect of prevention's accountability circuit (and the wider institutional complex of which it is a part), is that it organises people's work around multiple different interventions. New preventive technologies, including both medications and ‘lifestyle interventions’, are being increasingly promoted to address the burden of CVD (demonstrated as being ‘evidence based’ using dominant research methodologies — Chapter 4). Indeed, the institutional construct of ‘prevention’ itself comprises piecemeal interventions. In the care of most patients, no single HCP plays a central and coordinating role — their needs are addressed through different interventions each following a standardised model, and each taking place with a different HCP or other professional (and

¹⁶² E.g. Dr Jack, Levi and others whose accounts are not highlighted in this thesis.

perhaps in multiple locations and at different times). As a result, each professional involved in a patient's care is limited to the latest textual representation of that patient as provided on the electronic record.¹⁶³ The wider institutional coordination of appointment systems within general practice means that they may have little previous knowledge of the patient and little opportunity to build the type of relationship likely to support care practices — the kind of relationship which includes an ongoing 'conversation' about the issues relating to improving health over time. Although some attention has been given to the importance of 'continuity of care' and 'therapeutic relationship' in general practice, these notions are frequently represented as unrealistic patient "demands" which are incompatible with speedy access to appointments and with modern working patterns (e.g. Baird et al., 2016) and as relevant only to patients with multiple (complex) health conditions (e.g. Haggerty et al., 2003). As a result, new models of care are being developed which emphasise 'management continuity' provided by teams of HCPs and coordinated by a named GP, instead of ongoing *relational* continuity (Baird et al., 2016). These understandings of 'continuity' risk abstracting patients' concerns into theoretical ideas and strategies in which the provision of 'care' and 'conversation' are lost.

9.6.1 'Evidence based' interventions in practice

Prevention, as a set of fragmented interventions, is held together by institutional processes which are designed to eliminate the many uncertainties about evidence and the different potential approaches to addressing preventive needs. The accountability circuit creates a kind of 'binary opposition'¹⁶⁴ between activities which are constructed, and activated at the frontline, as 'evidence based', and those which are not. This narrowed form of scientific knowledge rejects alternative ways of knowing which have not been 'proven' through a randomised controlled trial (ideally), and then badged as an 'evidence-based intervention' in clinical guidelines (which include economic models of cost effectiveness — 2.6). Wildwood Social Club (5.7), although apparently making a significant contribution to improving the general health of individuals who are

¹⁶³ Or sometimes on a referral form, as when a patient is referred to 'lifestyle interventions'.

¹⁶⁴ See Childs and Fowler (2006).

likely to be at risk of CVD, does not hold sway within the authoritative frame of 'prevention'. In order for it to gain recognition, it would need to be standardised as a 'complex intervention' which healthcare managers could 'pick off the shelf' and implement in their own regions as an 'effective intervention'. The process of creating the 'evidence base' for such an intervention would inevitably strip the social club of practices which are difficult to measure, and would not account for the local availability (or unavailability) of skills and resources. The club leader's (Iris') individual skills, her personal (voluntary) commitment, and the local facilities available cannot be packaged in this way.¹⁶⁵

This study raises questions about whether preventive interventions are actually as clinically beneficial (for individuals) as the population level performance metrics indicate — whether they will minimise people's chances of dying prematurely, or save healthcare costs, even when viewed through a 'scientific', epidemiological lens (Chapters 2 and 4). The metrics I have highlighted are built on multiple calculative formulae which enable an algorithmic construction of impact on 'burden of disease'. They are promoted by policymakers who, operating under the influence of (quasi) market logics (Harrison and McDonald, 2007; Erikson, 2016), are under pressure to demonstrate their region's achievements (Chapter 2 / 8.6). It is therefore possible (even likely) that the picture painted by these CVD prevention metrics, although based on 'good evidence' (from randomised controlled trials and the like), may overestimate the true impact of individual preventive interventions on future disease in the population. A patient who follows a limited range of preventive activities promoted by the accountability structures to 'reduce their risk' (e.g. by religiously taking blood pressure medications, lipid-lowering medications and so on), whilst being unsupported to manage aspects of their lifestyle affecting their everyday health, may achieve little or no tangible (immediate or long-term) health benefit from these interventions, which may instead cause them considerable immediate

¹⁶⁵ Another by-product of the strict delineation in practice between interventions which are 'evidence based' and those which are not, is that preventive practices which are likely to have a huge impact on health and wellbeing (e.g. stopping smoking, eating nutritious food) are lumped together with those whose impact is likely to be much more limited (e.g. blood pressure medications or statins in the absence of lifestyle change), making it difficult for HCPs and patients to see which interventions will have greatest benefit (Chapter 8).

everyday troubles. In any case, as I have highlighted, a small extension of life-span may not be of primary importance to many.

The approach to evidence promoted through prevention's accountability structures results in pharmaceutical interventions being prioritised over approaches which are more likely to improve patients' *overall* health and wellbeing. Although a variety of so-called 'lifestyle' interventions are included in the authorised suite of 'evidence based' preventive interventions (*Figure 6*). HCPs know that, in practice (outside a research study setting), these interventions are frequently unsuccessful. (My analysis in Chapter 5 suggests that the providers of these programmes frequently do not have the skills or resources to provide truly adaptive support for patients to make lifestyle changes.) My data suggest that, as a result, HCPs extrapolate that patients' wider attempts to change their lifestyles are likely to be futile — especially in disadvantaged communities (Chapter 5). HCPs are therefore reluctant to invest time and energy into promoting and supporting non-pharmaceutical preventive approaches, which also have little visibility within current prevention metrics.

9.6.2 New interventions

Many aspects of people's lives which impact on their health improvement work are far-removed from the suite of 'interventions' proffered within the risk management discourse and prevention's accountability circuit — services relating, for example, to aspects of health that have been constructed as 'social', such as housing or victim-support (Chapter 5). There has not been space here to discuss other factors, such as the acute experience of isolation many patients experience, which clearly impacts on their ability to implement preventive activities into their lives (an experience which is likely to be compounded when care practices are institutionally organised out of HCPs' prevention work). Policymakers are attuned to these social problems because there are compelling theories about how they account for low uptake of preventive interventions. Consequently, some policymakers and researchers are turning their attention to solutions such as 'social prescribing' (e.g. Brandling and House, 2009), interventions such as those to combat (for example) loneliness (e.g. Holt-Lunstad and Smith, 2016), or efforts to increase the length of appointment times in health centres serving deprived communities (e.g. GPs at the Deep End, 2010; Chew-

Graham et al., 2013) — to be tacked onto the ideological framework of prevention. These additional interventions respond to the gaps exposed when practices at the frontline are orientated towards textual measures of accountability, and when social environments, particularly associated with poverty, are structured to perpetuate unhealthy behaviours (Bissell et al., 2016). Some of these specifically attempt to 'join-up' the different interventions and services being promoted. Although these initiatives validate the problems and may contribute something useful within the existing social organisation of preventive care, they are likely to act as 'sticking plasters' covering over patients' more fundamental need for care — the kind of care in which HCPs and patients work together, and which adapts and compromises around the many uncertainties of living with risk or disease. *Some* solutions may alleviate *some* of the problems created by prevention's accountability circuit, but it is unlikely that additional, often 'bolt-on' solutions delivered by low-skilled workers offering packages of 'advice' or 'support', will unproblematically mesh together interventions, or facilitate care practices that are genuinely responsive to patients.

9.6.3 Navigating multiple interventions

Some division of prevention work into individual interventions is undoubtedly inevitable (and likely very necessary). Given this, consideration is needed to learn about how patients may be helped with navigating different available preventive interventions, and also how to direct them towards other (accessible and individualised) services to improve their health. As this study has shown, preventive work is inevitably messy when applied to everyday situations. Prevention practices are predicated on the possibility and desirability of identifying and targeting particular *aspects* of a person's life and body, even when that individual has multiple and interconnected preventive needs for which they would benefit from support. A focus on restricted, short-term interventions is exacerbated by the contracting out of 'lifestyle' interventions described in Chapter 5, as well as the division of labour which is integral to the structures for chronic disease management within the health centre. Patients need individualised support to join up and make sense of the different opportunities available to them — within the constraints which are inherent to their unique lives.

My argument is that the array of preventive technologies, designed to address textual constructions of the burden of CVD, generate a need for more adaptive 'care' practices, in order for patients and HCPs to weigh up whether, or how, to apply them sensitively within real life — to continuously “figure out” how to “attune the different viscous variables of a life to each other” drawing on various actors and interventions (Mol, 2008, pp.26, 62). The problems generated by coordinated accountability practices are not primarily with the interventions themselves, which for some patients may have many potential benefits. They are the result of interventions which are *applied robotically*, as simple solutions to textual constructions of highly-specified preventive 'needs' — problems resulting from patients being left alone to manage the tensions precipitated as these interventions conflict with each other, and with everyday life. Whatever the portfolio of interventions, HCPs may (within the current social organisation of preventive practices) appear like automatons, restricted to providing standardised solutions to people's complex preventive needs. As Julia commented in relation to HCPs at her health centre (see 1.2), “there's no doctoring these days, they're just like, it's just like, **automated**”. It is unsurprising that patients feel 'processed' without the relational continuity and professional expertise which are necessary in order to adapt preventive care to their individual needs and support them to improve their health.

9.7 What is important to patients?

The question 'what is important to patients?' has been a core part of this study. It underlies my IE focus on the disjunctures people face as their local, embodied knowledge comes into conflict with ruling, textually-constructed knowledge of their preventive needs. What is important to (and in the interests of) patients is often different to what is important to (and in the interests of) ruling relations. In framing the problematic for the study, I argued that patients *appeal for* care practices (5.8). Yet patients only rarely *express* their preventive needs using ideas about 'care'. Instead, they talk about not being able to have a “meaningful conversation” (see introduction to this chapter). Frustrations are expressed such as in Julia's challenge that “there's no doctoring these days”, in Naomi's impassioned outburst that the “doctor doesn't care”, or in Sarah's despondent comment that “it's the *quality* of life that counts”. Patients, I suggest, do not know

how to articulate their preventive needs for a 'conversation' (for 'care') within the dominant risk management discourse. Instead, they are organised to understand themselves as 'in control' and able to freely select and implement the 'appropriate' interventions which will 'reduce their risk' (EX27). It is only when patients encounter problems in applying institutional preventive practices to their lives that cracks open up between the preventive care on offer and their own needs.

A particular example of the cracks which open up, relates to the disjuncture between burden of disease metrics and 'quality of life' as understood by patients. The subject of death (in the form of mortality statistics) features prominently within the social organisation of prevention; in policy representations, *avoiding* death (and disability, which at some point may lead to it) are the basis for preventive work (see Chapter 2). My analysis however suggests that *statistical* 'outcomes' such as death or a 'cardiovascular event' are distant and frequently irrelevant to patients in the face of other pressing concerns (as also discussed in other studies (for example, Warin et al., 2015 talk about the "short horizons" of those living in a disadvantaged community)). This is not to imply that patients are intrinsically irresponsible, or 'fatalistic' as some research (e.g. Honey et al., 2014) and one of my policymaker informants suggested. Instead, I observed that the reality of daily life makes it extremely difficult for some to prioritise the implementation of lifestyle changes over other more pressing issues such as housing, employment, family commitments, or even immediate suffering from current symptoms of their health issues. An almost endless variety of different issues impacting on daily life and 'lifestyle' affect not only the most disadvantaged but also those who live in relatively comfortable circumstances (see, for example, my account of Mrs Green's Health Check in 6.2). Instead, they look for 'quality of life', not as statistical measures on which GBD analyses are built (understood as directly aligned with mortality outcomes), but a different sense of 'quality', made up of good relationships and practical compromises in the face of multiple uncertainties (4.4) and between different *realistic* (and sometimes unpalatable), options and outcomes 3.3.2.

Prevention, articulated to the GBD discourse, fails to recognise this appeal for immediate care (responding to a range of health concerns including, but not

limited to, the management of risk conditions). Within the current organisation of healthcare, it perhaps seems counter-intuitive that 'prevention' should require a discussion of life's (and death's) big questions. After all, these discussions are frequently understood to be most relevant in cases of terminal illness and end-of-life care (Gawande, 2015). However, this study has shown both the relevance of such considerations in peoples' decisions about their health, and also the ways in which they are rendered largely irrelevant within prevention's accountability circuit.

9.8 Patients' work in prevention

The institutional complex organising CVD prevention practices *creates additional needs for adaptive care* practices at a local level, as new preventive practices enter into people's lives. It also organises these types of practices out of frontline work, as HCPs are drawn into its accountability circuits. My data have shown however that patients want to be *involved in a conversation about how they can best act in light of their circumstances*. They frequently indicate that they want to be involved in "shaping a good life" (Mol, 2008, p.47), to be "active patients" (ibid., p.91), but that this requires support from HCPs as different situations arise, and as circumstances change over time. This does not mean that they wish to abdicate responsibility to HCPs. Resonant with my data is Mol's (2008, p.92) argument that, as part of good care practices, patients still have to "take a lot upon [themselves]" and they still have to make choices. Prevention's accountability circuit creates numerous situations of choice for which patients are not always well-equipped; they do not have the resources at their disposal to work out how to handle the different options in practice. Their knowledge about what is required, and what they are able to undertake, may be at odds with the forms of knowledge embedded in ruling relations. However, my data suggest that even patients in challenging everyday circumstances are often willing to be part of collaborative work to improve their health.

Within prevention's institutional complex, the efforts of patients, and patients themselves, are objectified. Discussion of patients' activities is dominated by the ideological construction of 'involvement' which includes conceptual notions that they should "take prevention seriously", be more "active" in managing their own health, or take on more "self-care" (Chapter 4). 'Involvement' in this context

usually relates to taking particular action (7.5) — action that will generate positive QOF metrics which are crucial to the operation of prevention's accountability circuit (Chapter 8). These ideological framings of involvement oil the mechanism of the accountability circuit — funnelling patients into making decisions which demonstrate institutional preventive 'success'. Questions about whether patients attend a Health Check or a lifestyle intervention, whether they will change their diet, whether they will question the prescription for preventive medication which their HCP is recommending, have authoritatively 'right' answers which the ruling relations organise and enforce — even if various systems are in place to 'allow' for dissent. These questions are framed as one-off decisions (the responsibility for which is to be the patient's, and for which the patient is then held accountable) rather than as "practical tasks" which can be adapted and changed over time (Mol, 2008, p.93). Conversations and individualised attention to patients' preventive needs are frequently organised out of prevention practices.

Prevention's accountability circuit does not impact on all patients equally or in the same way. It coordinates patients' prevention practices (and their 'potentiality to act') in relation to where they are institutionally located.¹⁶⁶ As Smith (2006b, p.65) describes:

"[...] people, as individuals, arrive at any moment with their own distinctive histories, their distinctive perspectives, capacities, interests, concerns and whatever else they may bring as a potentiality to act in a given setting"

Each individual has a socially organised 'location' and resources that are coordinated (ruled) by the social relations organising preventive practices (see 3.2). Although the prevention practices into which workers (patients and HCPs) are drawn *may* support people to improve their health (e.g. encouraging a lifestyle change as in Dan's story, or identifying a dangerous risk condition for which they will benefit from treatment), they may also lead to interventions, and preventive interactions with HCPs, which have various negative consequences for patients' wellbeing and ongoing healthcare.

¹⁶⁶ As described in 3.7, the IE approach does not assume that everyone in the standpoint location experiences social relations in the same way.

Some patients are, of course, more able to do the work involved in engaging a network of support and resources than others. Like the activist GPs in Chapter 8, patients too *may* be able to work around prevention's accountability circuit to generate collaborative care practices with HCPs. However, in the absence of practically-orientated dialogue about what can realistically be achieved and what 'fits' with their everyday lives, many people (to various degrees) *take on their own* care work (Mykhalovskiy and McCoy, 2002), engaging an alternative network of support to enable them to coordinate their own "tinkering with bodies, technologies and knowledge" (Mol, 2008, p.14). I am not talking about the ideological constructs of 'self-care' discussed above (the conceptual ideas designed to oil the mechanism of the accountability circuit), but am highlighting the practices into which patients are drawn in order to make sense of preventive technologies, and to adhere to their ruling configurations. This type of work (the work patients undertake as noted in this study) has resonance with the "DIY" health work described by Will and Weiner (2013) and may, to a greater or lesser degree, conform to authoritative understandings of preventive action (see 5.7/7.4). It includes, for instance, harnessing their own resources to search the internet for details of preventive treatments and then working out for themselves how to act (see Dan's story in Chapter 1). Patients *may* then bring the knowledge gleaned from this type of work to their healthcare consultations, querying or challenging authoritative knowledge about interventions (e.g. Dan, Bailey). They *may* find that their HCP is receptive to their appeals to adapt preventive interventions around their individual circumstances, and willing and able to work around the directions and monitoring of the accountability circuit. However, these appeals for individualised support inevitably come up against the authoritative practices of prevention which, as I showed in Chapter 8, are designed to be extremely challenging to work around.

I have particularly emphasised the work of patients who attempt to *engage HCPs* in supporting them, and in fitting preventive interventions to their lives — in having a 'conversation' (or conversations). It is important to patients that these 'conversations' involve not just the one-way provision of statistics about risk, but also support to understand which interventions "make sense" aetiologically (see 7.4) — a finding which tallies with Polak's (2016) study of patients' decision-

making about statins). As I have shown, they frequently need support to find a good route through the different possibilities *in practice*. This work, I suggest, is an important form of contemporary preventive 'health work' (Mykhalovskiy and McCoy, 2002) which is largely unrecognised in official representations of preventive care. I argue that, with the accountability circuit explicated, it is little surprise that HCPs frequently provide a combative or restricted response when patients attempt to be involved in adaptive care practices that contravene the ruling relations of prevention. As a result, patients have to work hard to maintain positive relationships with HCPs, striving for meaningful outcomes and adopting performances that cover over the tensions generated (see Gale et al., 2011 who also showed that most patients are keen to follow HCPs' recommendations even when they conflict with their own concerns about taking medications). My data challenge the authoritative characterisation that it is only HCPs who struggle to 'engage' patients in prevention work (see 4.5), and show instead that, from the standpoint of patients, it is they who often work to 'engage' HCPs. Some, like Naomi, do not have the communication performance necessary to undertake this engagement work successfully, and may find themselves neglected or "abandoned" (5.7) when various preventive technologies — such as medications, lifestyle advice and so on — are stipulated, but they are left alone to adopt and live with them. Their work may be particularly difficult when they are informally categorised by HCPs using conceptualisations such as 'unmotivated', 'disengaged', or not 'taking prevention seriously' (see Chapters 2 and 5).

9.9 HCPs' work in prevention

Although many HCPs (both activists and others) understand themselves as practising 'patient-centred care' and 'shared decision-making', what actually happens in practice is shaped by ruling relations. Decisions about interventions are organised around ideas about (good), well-informed choices, and algorithmic guidelines that are expected to equip patients with the skills and resources to follow through on the 'prescribed' approaches to risk (Chapter 7). The textual organisation of prevention (based on binary knowledge in clinical guidelines about which interventions are, or are not, 'evidence based') make it difficult for HCPs to access and utilise information on which they can base nuanced (collaborative) conversations about preventive options (e.g. about the "scale of

benefit" of different medication options (8.2)). As I have shown, their work is also organised through other textual mechanisms to avoid such conversations.

However, as I have shown, some HCPs attempt to promote conversations that align with Mol's 'logic of care'. However, they find that, when they involve themselves in "facilitating" a "conversation" to help patients find out "what it is they want" (see Dr Smart's account in 8.2, EX32), they have to defend themselves against the charge of 'paternalism' (McCartney et al., 2016). The activist GPs I highlighted in Chapter 8 frequently use the concept of 'clinical judgement' as illustrated in EBM's ideal model (3.1), but they know that within prevention's accountability structures, active involvement in a patient's decision may be framed as potentially 'paternalistic' and (paradoxically) *contrary* to dominant notions of patient-centred care in which patients are expected to *make informed choices* themselves (Coulter, 1999). Worse still, they may be accused of *influencing* patients' choices in a way which may be characterised as 'poor care'. GPs' concerns about how to position their own therapeutic involvement point to tensions in the clinical community over what "good medicine" should look like in practice, and to a fear that guiding patients towards particular choices (especially those which do not form a part of prevention's accountability circuit) may be construed as an outdated type of care in which HCPs assume that they "know best" and make "decisions on behalf of patients without involving them" (Coulter, 1999). Although it is clear that patients do not want arrogant 'doctor knows best' from their HCPs (and they *do* want to be listened to), they also want *active support* to improve their health. For example, Dean tells me that he wishes that HCPs would be "tougher" with him — in other words that they would more *actively support* him with the detail and ongoing challenges of how to manage his diabetes.

The accusation of 'paternalism' however, has particular ruling authority over activists' work. In my data, activist HCPs drew attention to the need for 'clinical judgement' (see Chapter 8) but did so by emphasising *compatibility* with the ideological frame of 'patient-centred care'. Dr Stefan argued, for instance, that activists' work to challenge the 'guideline-driven culture' of general practice would lead to better experiences of care for both patients and HCPs — "eventually we'll be happier, because we're practising individualised [patient-centred] medicine

and we'll have our professional autonomy back" (emphasis mine) — see 7.5. Although EBM's 'ideal model' (*Figure 13*) suggests that clinical judgement can be successfully integrated with both research evidence and patient preferences (acknowledging the limitations of the evidence base and patients' individual needs), I argue that prevention's accountability circuit is fundamentally at odds with this type of clinical autonomy.

9.10 Accountability practices: hiding in plain sight

The social organisation of troublesome preventive practices is typically not obvious to those participating in them — the textual mechanisms by which they are coordinated happen "behind [their] backs" (Griffith and Smith, 2014a, p.348). It might seem, for instance, that frontline HCPs (especially GPs), with their privileged access to internal policies, funding arrangements, professional bodies and the like, would see clearly how their work is organised. However, it is an inevitability of working within an institutional complex that there are limits to what is knowable from particular locations in relation to it. It is not possible for HCPs to 'join the dots', either in relation to how their work is organised from 'above' (the remote institutional processes shaping CVD prevention), or in relation to how their own preventive practices impact on patients — they are not privy to other people's practices in different locations within the institutional complex. Individual informants, although experts in their own work, will therefore likely be unaware of the *coordinated and circular practices* mapped here, and the ways in which national and local policymakers' work is orientated to produce a textual construction of better health outcomes and reduced future costs. Patients, who are located at a greater distance from the textual mechanisms of prevention's accountability circuit, are even less likely to be aware of the ways in which their experiences are socially organised.¹⁶⁷ Although Dan and others produce explanations for their experiences, I have shown that these typically fall short of insight into the central organisation of their experiences — the explanatory frames point to *symptoms* rather than *causes*. For instance, my data suggest that patients' experiences of apparent arrogance and poor communication from their

¹⁶⁷ See Hannon et al. (2012) for example, who demonstrated that patients were largely unaware of QOF incentives.

HCPs are organised to occur (promoted) within this accountability circuit, as HCPs work to produce accounts of their work which demonstrate its value and efficiency and are orientated away from the more humble practices of listening and tailoring their care to individual patients.

9.10.1 Reframing 'good care'

Intrinsic to accountability circuits are the ideological practices and 'coordination of consciousness' which drive them (see 3.2). A plethora of ideological ('shell') concepts (such as: 'patient-centred care'; 'shared decision-making'; 'involvement'; and so on) create the abstracted impression that preventive practices are genuinely supporting patients to improve their health (see Chapter 7). The ideological constructions of frontline preventive interactions in particular, which are splattered throughout CVD prevention policy (and healthcare practice more generally), are shaped and subject to the dominant accountability practices I have shown, creating abstracted notions of 'what happens' which are often significantly at odds with what happens in frontline practices. They enable HCPs, researchers, policymakers (and even patients and the public) to "speak about [prevention] one way" while often patients speak or *experience* it another (Campbell and Gregor, 2002, p.52).

The extensive use of ideological concepts (based on ideas of 'shared decision-making' and the like) provides a terrain where the accountability practices blur into the background — often framed as simply administrative, or as (good) objective approaches to managing the 'quality' of care. However, accountability practices are not just 'in the background' but are increasingly integrated into understandings of what 'good care' involves — my data show that when policymakers talk about 'good care', performance metrics frequently dominate. Similarly to Rankin and Campbell's observation that the term 'quality' contained a blend of managerial and more 'colloquial' frontline understandings (3.2), in prevention practices the notion of 'good care' harnesses HCPs to accountability practices built on disease prevention metrics.

This observation about the authoritative, managerial use of the term 'care', contrasts with Mol's observation that discussions about 'care' within the healthcare sector have been more restricted than those in the social science arena (which have been concerned with the broader social effects of care). Mol

and colleagues (Mol et al., 2010, p.12) argue that, within healthcare, “the great variety of activities and interactions typical to care settings, [has been] divided up into separate ‘interventions’ plus the ‘relational work’ that facilitates their delivery”.¹⁶⁸ ‘Care’, she says, has been cast in the relational terms of “kindness, dedication and generosity” (2008, p.5).¹⁶⁹ This IE analysis however describes how, within general practice, ideas about ‘care’ no longer correspond to the ‘relational work’ which facilitates the delivery of ‘interventions’; instead, policymakers have colonised the idea of ‘care’ such that it is dominated by performance metrics — accountability practices are embraced as central to this emerging conception. Facilitating the delivery of interventions (and the accountability circuit more broadly), are ideological framings which are more limited in their scope, such as ‘patient-centred care’, ‘patient experience’, ‘shared decision-making’ and ‘involvement’. These appear to have replaced notions of ‘care’ as the ‘relational work’ which is organised to ensure the smooth-running of accountability practices and the multiple interventions involved in them.

9.10.2 Disorienting activist attempts to improve practice: the problem of ideological concepts

As I have shown throughout this thesis, the terrain of preventive care is crowded with ideological language and practices, which organise activists’ attempts to promote the kind of care practices from which many patients would benefit. Contemporary discussion of ‘shared decision-making’ usefully illustrates this. Ruling relations have framed ‘shared decisions’ as one-off moments in which HCPs should share information, and patients should decide on a course of action — transactions consisting of ‘sharing’ (HCPs) and ‘deciding’ (patients) which are abstracted from patients’ ongoing needs for support (see 7.3/7.5).¹⁷⁰ Activist work to produce more (and better) information (4.4.2) to facilitate these preventive interactions may have benefits. Such activism is effective, to some extent, as a way to challenge the ruling practices in which medications are promoted to

¹⁶⁸ As Mol (2010, p.12) points out, this division “made it possible to use the methods of epidemiology to explore which interventions [are] ‘effective’ and which [are] not”.

¹⁶⁹ Described by Pols and Moser (2009) (following Mol’s approach) as “warm” notions of care which are constructed in opposition to some technologies (whilst facilitating others).

¹⁷⁰ This is a simplistic representation but one based on dominant discussions in frontline practice and in clinical/academic arenas.

patients. However, when this work focuses only on discrete choices and the provision of information to support these decisions, it fails to challenge the ruling frame in which accountability practices push-out care practices.

Additionally, ideological ideas confuse and disorientate activists' work to promote alternative, more subversive understandings of these terms — interpretations which, for instance, encourage HCPs to facilitate conversations which *may* lead to decisions about preventive medications which *inhibit* prevention's accountability practices (see Chapter 8). When activists, for example, attempt to recolonise the idea of shared decision-making (to promote a 'true', more patient-orientated, and (arguably) 'original' essence (Chapter 8)), policymakers and frontline HCPs tied to dominant ideological conceptualisations may continue to interpret their work within the dominant ideological frame. This leads them to, for instance, position such activism as superfluous based on their understanding that (for example) 'shared decision-making' is already happening (see 3.5 and 7.5 on 'institutional capture').

Similarly, when academics, clinicians, and professional groups promote the importance of practices which are sensitive to individual needs and complexities (see, for example, Marshall, 2015; Royal College of General Practitioners, 2012), these appeals are likely to be interpreted as facilitating a harmonious set of practices known as 'good quality care' which, as I discussed above (9.10.1), is orientated around accountability practices. Although institutional rhetoric promotes such improvements, they are interpreted and reformulated within ideological frames organised to *support* (and legitimise) the circuit. Within these frames, this work, which has the potential to challenge the social organisation of preventive practices, may be understood only to promote the softer, 'relational' aspects of clinical care which facilitate the delivery of preventive interventions. Policy and academic debate often becomes abstracted into a battle of *conceptual ideas* about what should, and should not, happen in frontline practice — rather than a discussion of the actual *practices* involved, and how they are organised.

9.11 What does this study contribute to understandings of CVD prevention?

This study is (to my knowledge) the first to employ institutional ethnography to capture the broad range of practices which make up 'cardiovascular disease

prevention' in England. Many other researchers have used ethnographic, observational, or interview methods to detail some specific practices or experiences related to a particular risk condition (e.g. Hinder and Greenhalgh, 2012) or technology (e.g. Saukko et al., 2012). However, these analyses have not been assembled to create a 'bigger picture' of CVD prevention as a whole. Not only does this study put together this 'bigger picture', but it is also unique in employing institutional ethnography's distinctive theoretical approach to examine prevention. The IE approach has structured the whole process of analytical enquiry — including the review of literature and policy, the approaches to data collection and the (concurrent) analysis, and has allowed me to map a section of the terrain I set out to explore, and to show *how* taken for granted institutional relations shape HCPs' and patients' preventive activities in ways that are troubling.

Using IE's theoretical toolkit, I have explored not only the local practices in which HCPs and patients participate as they interact in the general practice setting, but have also followed clues into the 'mountain range' — an institutional complex of ruling relations (1.3). This research was grounded by troubling practices that arise in the standpoint of patients, which led to identifying and following clues to learn about, and explicate, how patient experiences are *organised*. This is not to imply that the tensions are part of a "masterplan of rule" (see the critique of some research analyses by Mykhalovskiy, 2001, p.152); rather they are the inevitable consequences of ruling structures which pull policymakers, HCPs, and patients into ideological solutions to address a problem formulated as the 'burden of disease'. The IE approach has enabled an analysis that expands critique beyond the local arenas where others have conducted ethnographic studies of healthcare, and provided a way to move beyond local perceptions or practices that only broadly gesture to the influence of institutional processes as 'culture' or 'context' (3.2).

Examining and linking people's practices across the continuum of prevention work contributes to a variety of existing critiques across various fields. In particular, I have situated this study as a contribution to anthropological analyses of 'global health' such as those collated by Adams (2016) (see Chapter 2). It also provides an innovative approach through which to add to existing research

relating to 'patient experiences' of CVD prevention, which more commonly focus on, for example, patients' expectations of interventions (e.g. the Health Check), their ability to understand risk statistics, or on their preferences in relation to medication-taking (Chapter 4). It helps to demonstrate how the tensions experienced by patients faced with preventive decisions are organised, empirically showing the practices which lead to troubling experiences for patients. These experiences have been variously portrayed in critical analyses using terms such as 'overdiagnosis', 'responsibilisation', 'labelling', patient 'values and preferences', and so on. Although many analyses have pointed to the institutional organisation of healthcare services, few have empirically investigated it (see Gale et al., 2012). Notably, a few have considered the textual organisation of HCPs' work in general practice; this work adds to their analyses which have, for instance, pointed to the coordinating effects of the QOF, or computer templates, on frontline patient care (e.g. Chew-Graham et al., 2013; Swinglehurst and Greenhalgh, 2015). This study also provides practical insight to inform (frequently conceptual) discussions about the practices of EBM, SDM and the like, and how they should be improved (e.g. Lambert, 2006; Heneghan et al., 2017); it suggests that addressing the issues Greenhalgh et al. (2014) identify will require those promoting 'real EBM' also to chip away at prevention's accountability structures (see 3.1, *Figure 12*).

I have shown that the activation of prevention's accountability circuit organises the work of everyone involved in it, not least HCPs working at the frontline and the patients who book appointments with them. Preventive practices (such as those embedded in the Health Check programme), are driven by metrics of risk prediction and economic modelling, and have been organised to disengage from actual patients' needs. The algorithms and metrics with which prevention's accountability circuits are put together cannot easily accommodate collaborative and adaptive conversations and therapeutic approaches. Patients are processed through a series of multiple interventions and apparent 'choices' that can have a devastating impact on their experience of healthcare services and their ability to engage the preventive support they need. I have exposed how an 'absence of care' is organised, how what Mol calls a 'logic of choice' is socially organised to triumph over a 'logic of care', and how prevention's accountability circuit weakens

care practices. I have shown that institutional knowledge about prevention is so tightly orientated to 'risk management' discourse (feeding into accountability systems to reduce the 'burden of disease') that patients and HCPs are pulled into an unwitting participation in its dominant way of thinking and acting. Indeed, this objectified knowledge may overwhelm their own knowledge of preventive needs. I have particularly highlighted the 'work' in which patients participate to maintain relationships with HCPs in the hope that they may facilitate a 'conversation'.

I have shown too how accountability practices are creating all kinds of tensions for HCPs who want to do the best for their patients, and are detrimental to HCPs' professional identity (Chapter 8). There is considerable evidence that many are becoming disgruntled and leaving the profession. The following comment by a GP summarises the acute sense of disillusionment amongst GPs who feel that they are no longer able to address the 'caring' ("welfare") aspects of their role:

"I felt like I was working in a caring profession. So why do I, and most other GPs I know, now feel so disappointed and unhappy with our profession. What has happened? Surely life should be easier and better with no nights or weekends on call, and more part time work still affording a good living. Yet I have not met a happy, relaxed GP for years, with most bemoaning a system that has so little to offer unless the correct boxes are ticked, with little regard to patient welfare. I certainly no longer feel I am regarded as a caring professional by a Government that is obsessed by figures and cost" ('Con', responding to King's Fund blog post (Murray, 2014)).

Mol's loose understanding of 'care' (3.3.2) has been useful to assemble and bring "coherence" (Mol, 2008, p.12) to the apparently-unrelated tensions which appear when prevention's diverse ruling practices enter into HCPs' and patients' work. Mol's work opened up a field of empirical problems which I have explicated using IE. Her descriptions of 'care' resonated with the accounts of the standpoint informants recruited into this study, which confirm that patients value being involved in "attuning the many viscous variables of a life to each other" (Mol, 2008, p.62). While IE's mode of enquiry resists ruling conceptualisations which subjugate people's local experience, Smith (2005b, p.7) nonetheless emphasises the importance of language in activists' work, describing the struggle to find alternative ways of talking about everyday experiences and finding terms which

“gave shared experiences a political presence”. Mol’s vision of ‘care’ has the potential to usefully support activists’ work: it provides a common platform and terminology for those wanting to promote individualised, adaptive care practices.^{171,172} Mol’s vision of care highlights that there other ways of delivering preventive care than those which currently dominate, and that, when this type of care is lacking, patients (and HCPs) suffer. It is important that these care practices are highlighted, or they are in danger of becoming extinct.

However a vision of care practices, and a knowledge that these are disappearing, is of little practical use to activists without an understanding of the institutional arrangements which organise this disappearance. My research provides an innovative map, a tool that can be used to improve prevention practices. Mapping a segment of the ruling relations of prevention suggests alternative solutions that rest within policymakers’ work and the institutional (textual) complex that drives what happens locally. It is likely that those working within healthcare services, and promoting improvements to care practices, may be better placed to see the practical opportunities to make changes to the textual organisation embedded in the institutional complex. Ultimately, it would require policymakers to find ways of adapting (reorganising) the coordinating practices of prevention in a way which re-orientates them towards relational, adaptive care practices. Institutional texts would need to recognise that the epidemiological, scientific evidence on which prevention’s accountability circuit is based (about ‘what works’ in prevention) is not the only knowledge that counts for patients — and is perhaps not the only knowledge which can actively shape healthier lives. It is difficult however, and likely inadvisable, to attempt to subject all aspects of preventive work to the measures and metrics of prevention’s risk management discourse (see Greenhalgh and Heath, 2010).

My analysis of prevention’s accountability circuit suggests that, if current ideological prevention practices progress unchallenged, new policy strategies

¹⁷¹ Mol elsewhere (2008, p.47) describes her call to strengthen care practices and ‘shape a good life’ as “patientism”.

¹⁷² In order for Mol’s ideas to be useful, they of course need to be adequately differentiated from ideological connotations of ‘care’ (see 9.10.1).

introduced to fix the problems associated with prevention's accountability practices are liable to limit or override activists' improvement efforts. This call to attend to the institutional complex comes with a caution. As I have shown and highlighted above, institutional relations are powerful, with multiple actors' interests aligned to them. It is important that those promoting the relational and adaptive types of healthcare practices highlighted here recognise that their efforts are vulnerable to being colonised by a managerial agenda — in the way that 'patient-centred care' or 'involvement' have been ideologically reformulated as a set of relational activities supporting the smooth operation of accountability mechanisms. As concepts are so easily colonised by management practices, activists need to relentlessly find ways of talking which challenge ruling relations, populating conceptual language with *actual practices* in order to make their objectives clear.

The year 2018 marks the 70th anniversary of the NHS, and a "public conversation" about its "health" as a well-loved institution (NHS England, 2018). Concerns continue to be raised about its sustainability, and the resources which it requires. Disease prevention has, once again, been highlighted by Simon Stevens, the Chief Executive NHS England, as a crucial part of the solution to the NHS's ills (BBC, 2018). This study has however exposed significant tensions within the practical delivery of preventive care. I have presented a two-pronged argument. First I have argued that the practical, 'grounded' care work which Mol (2008; 2010) describes, and which helps patients to adapt to, and make the most of, the increasing range of preventive 'technologies' (e.g. the opportunities for lifestyle support, medications and so on), could, and should, be more strategically promoted as the cornerstone of preventive care. In my view, many patients and frontline HCPs would prioritise the forms of care which I have shown are systematically excluded, or confined to patients' personal networks, within the social organisation of cardiovascular disease prevention. Second, I have argued that an important focus of improvement work should be on the accountability mechanisms, such as those explicated here, which are often overlooked. I have shown that it is these ruling institutional relations which 'organise out' the meaningful conversations which are so important to patients and which help them to actually implement change in everyday life and that this can have considerable

detrimental consequences for patients, both in terms of their work to improve their physical health, and for their ongoing relationships with healthcare providers.

This study has aimed to “express the standpoint of people” (Campbell and Gregor, 2002, p.128) — those who are the targets of institutional prevention work. The findings presented here may be useful to activists attempting to combat ‘Too Much Medicine’, to researchers, and to others with various allied concerns; in highlighting how patients’ experiences of preventive healthcare are *organised*, the empirical map developed in this study provides a resource for targeting their efforts. Ultimately, I hope that it will promote genuine, supportive care practices which will benefit patients such as Dan, Naomi, and the many others who have informed this study.

Appendix 1: Standpoint informants

Descriptive guide	Severity of risk ⁷	LOW	HIGH	HIGH	MOD	LOW	LOW	HIGH	HIGH	HIGH
	Estimated QRISK score ⁶	3%	50%	28%	15%	3%	3%	30%	22%	21%
	Particularly troubling lifestyle risk factors ⁵					Y			Y	Y
	Following dietary advice? ⁴	Y		Y	N			Y	N	
	Following exercise advice? ³	ACTIVE	Y	Y	N	ACTIVE	ACTIVE	Y	N	ACTIVE
	LOW PHYSICAL ACTIVITY	Y?			Y	Y	?		Y	
Risk factor identified by informant	UNBALANCED DIET	Y?			Y	Y			Y	?
	SMOKING HABITS	Y				Y				
	WEIGHT PROBLEMS				Y	Y	Y		Y	Y
	HIGH ALCOHOL CONSUMPT.									Y
	HIGH CHOLESTEROL		Y					Y	Y	Y
	HIGH BLOOD PRESSURE							Y	Y	
	DIABETES/PREDIABETES							Y	Y	Y
	IMD Decile	3	8	8	1	7	8	4	2	7
Demographic data	IMD LSOA Descriptor ²	30% most deprived	30% least deprived	30% least deprived	10% most deprived	40% least deprived	30% least deprived	40% most deprived	20% most deprived	40% least deprived
	SELF DESCRIBED ETHNICITY	WHITE	INDIAN	WHITE	WHITE	WHITE	WHITE	WHITE	WHITE	WHITE
	M/F	M	M	M	F	F	F	M	M	F
	Age	44	83	74	71	43	48	67	59	69
	Pseudonym	Bailey	Baraka	Bill	Candice	Catherine	Charlotte	Dan	Dean	Elaine
	Unique participant code ¹	P05	MOP13	MOP03	MOP12	MOP07	MOP02	P07	P06	MOP14

Unique participant code ¹	Demographic data		Risk factor identified by informant							Descriptive guide									
	Pseudonym	Age	M/F	SELF DESCRIBED ETHNICITY	IMD LSOA Descriptor ²	IMD Decile	DIABETES/ PREDIABETES	HIGH BLOOD PRESSURE	HIGH CHOLESTEROL	HIGH ALCOHOL CONSUMPT.	WEIGHT PROBLEMS	SMOKING HABITS	UNBALANCED DIET	LOW PHYSICAL ACTIVITY	Following exercise advice? ³	Following dietary advice? ⁴	Particularly troubling lifestyle risk factors ⁵	Estimated QRISK score ⁶	Severity of risk ⁷
MOP05	Jane	62	F	WHITE	30% most deprived	3		Y	Y		Y				ACTIVE	Y		6%	LOW
MOP10	Jill	77	F	WHITE	40% most deprived	4		Y	Y						ACTIVE	Y		22%	HIGH
MOP06	John	48	M	WHITE	40% least deprived	7			?					?	ACTIVE	Y		4%	LOW
P08	Julia	79	F	WHITE	50% most deprived	5		Y			Y				ACTIVE			30%	HIGH
P09	Luke	65	M	WHITE	20% least deprived	9		Y							Y	Y		14%	MOD
MOP09	Naomi	43	F	WHITE	10% most deprived	1		Y			Y			Y	N	N	Y	3%	LOW
P02	Philip	55	M	WHITE	20% least deprived	9		Y							Y	Y		6%	LOW
MOP15	Raksha	55	F	OTHER	30% least deprived	8		Y						Y	ACTIVE	Y		5%	LOW
P04	Ron	67	M	WHITE	50% LEAST DEPRIVED	6		Y						Y	ACTIVE	Y		19%	MOD

Descriptive guide	Severity of risk ⁷	LOW	HIGH	LOW
	Estimated QRISK score ⁶	5%	24%	1%
	Particularly troubling lifestyle risk factors ⁵	Y	Y	
	Following dietary advice? ⁴		N	Y
	Following exercise advice? ³	N	N	ACTIVE
Risk factor identified by informant	LOW PHYSICAL ACTIVITY	Y	Y	Y
	UNBALANCED DIET		Y	
	SMOKING HABITS			
	WEIGHT PROBLEMS	Y	Y	
	HIGH ALCOHOL CONSUMPT.			
	HIGH CHOLESTEROL		Y	
	HIGH BLOOD PRESSURE	Y	Y	
	DIABETES/PREDIABETES		Y	
Demographic data	IMD Decile	1	1	3
	IMD LSOA Descriptor ²	10% most deprived	10% most deprived	30% most deprived
	SELF DESCRIBED ETHNICITY	WHITE	WHITE	PAKISTANI
	M/F	F	F	F
	Age	49	64	26
	Pseudonym	Sharon	Silv	Simrah
	Unique participant code ¹	P10	MOP11	MOP08

Footnotes to Appendix 1:

1. Participant codes correspond to the governance of the study
2. A measure of socio-economic deprivation. I generated this data by mapping the informant's postcode to Indices of Multiple Deprivation Local Super Output Area (LSOA). Informant postcode is categorised by decile (Open Data Communities, 2015).
3. My rough assessment of whether informants were following NHS advice about exercise was based on interview data and my knowledge of current advice (e.g. Department of Health, 2011a).
4. As above (e.g. Public Health England, 2016f).
5. 'Lifestyle' related risk factor (as opposed to biomedical marker such as blood pressure/cholesterol/sugars) which was particularly troubling the informant.
6. Estimated by completing the QRISK2 online tool (ClinRisk UK, 2016) with information supplied by the informant if this arose naturally in the course of the interview. (I did not ask questions specifically for this purpose, and I did not ask anyone to tell me their weight. Although informants sometimes told me blood pressure or cholesterol readings, I did not use these data.) Where the informant identified overweight as a risk factor, I used the following estimates for the BMI calculation based on categories of overweight/obese (NHS Choices, 2015) combined with my own subjective assessment. The QRISK2 tool is used by HCPs as part of the NHS Health Check (see Chapter 6). The 'severity of risk' uses categories (high, medium, or low) which were commonly referenced in clinical guidelines, frontline practice and patient information (NHS Choices, 2016c).

height (cm)	weight (kg)	BMI	
165	60	22	Normal (mid-range)
165	75	28	Overweight (mid-range)
165	91	33	Obese (near bottom of range)
165	127	46	Obese

About you

Age (25-84):

Sex: Male Female

Ethnicity:

UK postcode: leave blank if unknown

Postcode:

Clinical information

Smoking status:

Diabetes status:

Angina or heart attack in a 1st degree relative < 60?

Chronic kidney disease (stage 4 or 5)?

Atrial fibrillation?

On blood pressure treatment?

Rheumatoid arthritis?

Leave blank if unknown

Cholesterol/HDL ratio:

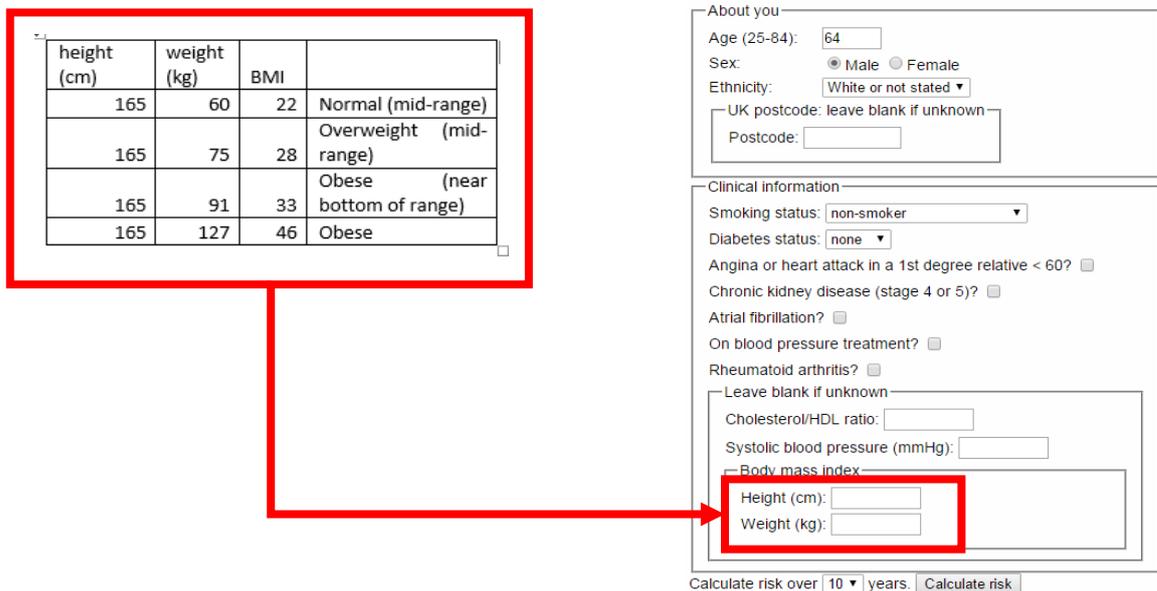
Systolic blood pressure (mmHg):

Body mass index

Height (cm):

Weight (kg):

Calculate risk over years.



Appendix 2: Extra-local informants

Unique participant code ¹	Pseudonym	Primary affiliation / role ²	Clinical qualifications?	Knowledge area ³
EL15	Alan	Public Health	N	Health Checks (English-region)
EL17	Annette	Public Health	N	Lifestyle' programmes (English-region)
EL22	Bill	Academic	Y	Incentives e.g. Quality and Outcomes Framework
EL12	Christina	GP - HCA	Y	Clinical practice (Riverbank)
OB04	Christina	see EL12	Y	Clinical practice (Riverbank)
EL10	Dr Abel	GP - GP	Y	Clinical practice (Wildwood)
OB01	Dr Abel	see EL10	Y	Clinical practice (Wildwood)
EL04	Dr Swift	GP - GP	Y	Clinical practice
EL20	Dr Jack	GP - GP / Academic	Y	Guideline development
EL05	Dr Smart	GP - GP	Y	Clinical practice
EL18	Dr Stefan	GP - GP	Y	Guideline development
EL19	Dr Sully	GP - GP	Y	Health Checks (English-region)
OB06	Emily	GP - HCA	Y	Clinical practice (Riverbank)
EL03	Ethan	GP - GP	Y	Social determinants of health
PA01	Iris	Community group	Y	Patient advocacy
EL02	Joanne	Academic / patient group	N	Patient centred care
EL07	Karen	GP - Practice Nurse	Y	Clinical practice (Riverbank)

Unique participant code ¹	Pseudonym	Primary affiliation / role ²	Clinical qualifications?	Knowledge area ³
OB03	Karen	see EL07	Y	Clinical practice (Riverbank)
EL01	Lance	Public Health	N	Public health management
EL08	Lena	GP - HCA	Y	Clinical practice (Wildwood)
OB05	Lena	see EL08	Y	Clinical practice (Wildwood)
EL06	Levi	Academic journal	Y	Research evidence
EL11	Luis	CCG	Y	Health Checks (English-region)
EL09	Lydia	GP - Practice Nurse	Y	Clinical practice (Wildwood)
OB02	Lydia	see EL09	Y	Clinical practice (Wildwood)
EL14	Sergei	CCG	N	Health Checks / commissioning (English-region)
EL21	Sue	GP - Administrator	N	Health Checks and Quality and Outcomes Framework data management
EL16	Suki	Public Health	N	Lifestyle' programmes (English-region)
EL13	Tanisha	Lifestyle provider / Health Trainer	N	Lifestyle' programmes (English-region)

Footnotes to Appendix 2:

1. Participant codes indicate observation (OB) or interview (EL).
2. Rough guide to the informant's job role. Several informants held multiple roles. I have not attempted to be comprehensive.
3. Knowledge area indicates particular areas on which interviews focused.

Appendix 3: CVD prevention policy

This list of policy documents is selective. It includes only publications which relate to broad aspects of CVD prevention policy. Although it includes a few particularly important clinical guidelines (relating to the integration of risk assessment), it does not include the many individual clinical guidelines which relate to the management of individual CVD risk factors.

Year	Publication Title	Reference
1999	Saving Lives: Our Healthier Nation	(Department of Health, 1999)
2001	National Service Framework (NSF) for Diabetes - Standards	(Department of Health, 2001)
2003	NSF for Diabetes Delivery Strategy	(Warburton, 2003)
2005	Joint British Societies' guidelines on prevention of cardiovascular disease in clinical practice (JBS2)	(Joint British Societies, 2005)
2006	Our Health, our care, our say: a new direction for community services (White Paper)	Department of Health / HM Government
2007	Prevention of cardiovascular disease: guidelines for assessment and management of cardiovascular risk	(World Health Organisation, 2007)
2007	The UK NSC recommendation on Vascular risk screening in adults over 40	(UK National Screening Committee, 2007)
2008	National Evaluation of DHDS ¹⁷³ Diabetes Screening Pilot Programme	(Goyder et al. 2008)
2008	Handbook of Vascular Risk Assessment, Risk Reduction and Risk Management	(Davies et al. 2008)
2008	Putting Prevention First	(Department of Health, 2008b)
2008	Vascular Checks: risk assessment and management: 'Next Steps' Guidance for Primary Care Trusts	(Vascular Checks Programme, 2008)
2008	Economic Modelling for Vascular Checks	(Department of Health, 2008a)
2010	Prevention of Cardiovascular Disease [PH25]	(NICE, 2010)
2012	Tackling Cardiovascular Diseases: Priorities for the Outcomes Strategy	All-Party Parliamentary Groups

¹⁷³ (Diabetes, Heart Disease and Stroke)

Year	Publication Title	Reference
2012	Updated The Handbook for Vascular Risk Assessment, Risk Reduction and Risk Management	(Davies et al., 2012)
2012	Preventing type 2 diabetes: risk identification and interventions for individuals at high risk	(NICE, 2012c)
2012	Services for the prevention of cardiovascular disease: Commissioning Guide [CMG45]	(NICE, 2012d)
2012	European Guidelines on Cardiovascular Disease Prevention in Clinical Practice (Version 2012)	(Perk et al., 2012)
2013	Cardiovascular Disease Outcomes Strategy: Improving outcomes for people with or at risk of cardiovascular disease	(Department of Health, 2013a)
2013	Health Check: Our approach to the evidence	(Public Health England, 2013c)
2013	Health Check implementation review and action plan	(Public Health England, 2013b)
2013	Understanding the Implementation of Health Checks – Research Report	(Research Works Limited, 2013)
2013	Living Well for Longer: A Call to Action to Reduce Avoidable Premature Mortality	(Department of Health, 2013c)
2013	The NHS belongs to the people: a call to action	(NHS England, 2013)
2014	Joint British Societies' consensus recommendations for the prevention of cardiovascular disease (JBS3)	(Boon et al., 2014)
2014	Lipid modification: cardiovascular risk assessment and the modification of blood lipids for the primary and secondary prevention of cardiovascular disease	(NICE, 2014f)
2014	CVD risk assessment and management	(NICE, 2014c)
2014	NHS Health Check programme standards: a framework for quality improvement	(Public Health England, 2014c)
2014	Encouraging people to have NHS Health Checks and supporting them to reduce risk factors	(NICE, 2014e)
2014	From evidence into action: opportunities to protect and improve the nation's health	(Public Health England, 2014a)
2014	Five year forward view	(NHS England, 2014a)
2015	Cardiovascular risk assessment and lipid modification: Quality Standard	(NICE, 2015b)
2015	NHS Health Checks: applying All Our Health	(Public Health England, 2015d)

Year	Publication Title	Reference
2015	NHS Health Check competence framework	(Public Health England, 2015c)
2016	Health Check Best Practice Guidance	(Public Health England, 2016e)
2016	Action on Cardiovascular Disease: Getting Serious About Prevention	(Public Health England, 2016a)
2018	NHS Health Check: stocktake and action plan	(Public Health England, 2018)

Appendix 4: Summary of QOF indicators directly relating to CVD prevention

These are taken directly from the 2015/16 QOF menu of indicators (see NHS Employers et al., 2015).

Indicators	Points	Achievement threshold
Atrial fibrillation (AF) indicator		
AF001. The contractor establishes and maintains a register of patients with atrial fibrillation.	5	
AF006. The percentage of patients with atrial fibrillation in whom stroke risk has been assessed using the CHA2DS2-VASc score risk stratification scoring system in the preceding 12 months (excluding those patients with a previous CHADS2 or CHA2DS2-VASc score of 2 or more).	12	40-90%
AF007. In those patients with atrial fibrillation with a record of a CHA2DS2-VASc score of 2 or more, the percentage of patients who are currently treated with anti-coagulation drug therapy.	12	40-70%
Hypertension (HY) indicator		
HYP001. The contractor establishes and maintains a register of patients with established hypertension	6	
HYP006. The percentage of patients with hypertension in whom the last blood pressure reading (measured in the preceding 12 months) is 150/90 mmHg or less.	20	45-80%
Diabetes mellitus (DM) indicator		
DM017. The contractor establishes and maintains a register of all patients aged 17 or over with diabetes mellitus, which specifies the type of diabetes where a diagnosis has been confirmed.	6	
DM002. The percentage of patients with diabetes, on the register, in whom the last blood pressure reading (measured in the preceding 12 months) is 150/90 mmHg or less.	8	63-93%
DM003. The percentage of patients with diabetes, on the register, in whom the last blood pressure reading (measured in the preceding 12 months) is 140/80 mmHg or less.	10	38-78%
DM004. The percentage of patients with diabetes, on the register, whose last measured total cholesterol (measured within the preceding 12 months) is 5 mmol/l or less.	6	40-75%
DM006. The percentage of patients with diabetes, on the register, with a diagnosis of nephropathy (clinical	3	57-97%

proteinuria) or micro-albuminuria who are currently treated with an ACE-I (or ARBs).		
DM007. The percentage of patients with diabetes, on the register, in whom the last IFCC-HbA1c is 59 mmol/mol or less in the preceding 12 months.	17	35–75%
DM008. The percentage of patients with diabetes, on the register, in whom the last IFCC-HbA1c is 64 mmol/mol or less in the preceding 12 months.	8	43-83%
DM009. The percentage of patients with diabetes, on the register, in whom the last IFCC-HbA1c is 75 mmol/mol or less in the preceding 12 months.	10	52–92%
DM012. The percentage of patients with diabetes, on the register, with a record of a foot examination and risk classification: 1) low risk (normal sensation, palpable pulses), 2) increased risk (neuropathy or absent pulses), 3) high risk (neuropathy or absent pulses plus deformity or skin changes in previous ulcer) or 4) ulcerated foot within the preceding 12 months	4	50-90%
DM014. The percentage of patients newly diagnosed with diabetes, on the register, in the preceding 1 April to 31 March who have a record of being referred to a structured education programme within 9 months after entry on to the diabetes register.	11	40–90%
DM018. The percentage of patients with diabetes, on the register, who have had influenza immunisation in the preceding 1 August to 31 March.	3	55-95%
Cardiovascular disease – primary prevention (CVD-PP) indicator		
CVD-PP001. In those patients with a new diagnosis of hypertension aged 30 or over and who have not attained the age of 75, recorded between the preceding 1 April to 31 March (excluding those with pre-existing CHD, diabetes, stroke and/or TIA), who have a recorded CVD risk assessment score (using an assessment tool agreed with the NHS CB) of $\geq 20\%$ in the preceding 12 months: the percentage who are currently treated with statins.	10	40-90%
Blood pressure (BP) indicator		
BP002. The percentage of patients aged 45 or over who have a record of blood pressure in the preceding 5 years.	15	50-90%
Obesity (OB) indicator		
OB002. The contractor establishes and maintains a register of patients aged 18 years or over with a BMI ≥ 30 in the preceding 12 months.	8	
Smoking (SMOK) indicator		

SMOK002. The percentage of patients with any or any combination of the following conditions: CHD, PAD, stroke or TIA, hypertension, diabetes, COPD, CKD, asthma, schizophrenia, bipolar affective disorder or other psychoses whose notes record smoking status in the preceding 12 months.	25	50-90%
SMOK003. The contractor supports patients who smoke in stopping smoking by a strategy which includes providing literature and offering appropriate therapy SMOK004. The percentage of patients aged 15 or over who are recorded as current smokers who have a record of an offer of support and treatment within the preceding 24 months.	2	
SMOK004. The percentage of patients aged 15 or over who are recorded as current smokers who have a record of an offer of support and treatment within the preceding 24 months.	12	40-90%
SMOK005. The percentage of patients with any or any combination of the following conditions: CHD, PAD, stroke or TIA, hypertension, diabetes, COPD, CKD, asthma, schizophrenia, bipolar affective disorder or other psychoses who are recorded as current smokers who have a record of an offer of support and treatment within the preceding 12 months.	25	56-96%

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