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# **Deciding about statins: a qualitative study of the way people come to take longterm preventive medication**

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I, Louisa Polak, confirm that the work presented in this thesis is my own.

Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed..... Date.....

## **Abstract**

This thesis set out to address a clinical puzzle: after being offered statins, why do many people end up not taking them? This question is relevant to two different enterprises, one aiming to improve public health through individually-targeted preventive interventions, the other aiming to help patients make evidence-based decisions about such interventions. To answer it, I used elements of a grounded theory approach to analyse data generated by interviewing people who had been offered statins. In the resulting account of the way people come to take statins, I situate the cognitive work of decision-making within a web of social practices.

Papers presenting many of my findings are incorporated into the thesis. The first draws on data from couple interviews, identifying ways in which these offer additional analytic purchase compared to individual interviewing. In the next two papers, examining the cognitive aspects of deciding about statins, I explore the way ‘need’ is constituted in relation to medication taken while feeling well. Participants reify test results, using them to account for medication decisions, but they do not use risk information in this way. This finding constitutes a challenge both to clinicians’ assumptions about communicating risk and to theoretical debates framing decision-making in terms of risk and uncertainty. The fourth paper focuses on the complex calibrations through which people negotiate tensions between conflicting norms concerning medication, negotiations complicated in the case of statins by the perception that they are a ‘lazy option’ chosen instead of a healthy lifestyle. This calibration work is required in order to construct a presentable account of ‘doing the right thing’; constructing this account is equated in the fifth and final paper with deciding what to do, a process that is inextricably entangled with other shared everyday practices.

I conclude with two discussion chapters. The first contributes to debates about information, knowledge and expertise. The second relates these debates to the everyday clinical problem with which the thesis began; I explore the implications of my findings for the practice of talking with patients about statins, situating this exploration within the project of reshaping the collection of practices that constitute evidence-based medicine.

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# **Chapter 1: Using statin decisions to consider prevention and decision making**

## **Introduction**

Many people who are offered statins do not take them. Of those who do accept an initial prescription, one in six never get as far as taking it to a pharmacy, according to one large study [Cheetham et al, 2013], and only about half are still taking the medication two years later [Jackevius et al, 2002; Naderi et al, 2012]. This phenomenon, generally referred to as low adherence, is frustrating for the researchers and policy makers who recommend statins for an increasing proportion of the population, and for the clinicians who spend time and effort explaining why taking them is recommended. The research project presented in this thesis set out to answer a simple question rooted in this frustration: how do people make up their minds about statins? In the course of the project, its aim evolved from an initial practical, biomedical aspiration either to improve adherence or to avoid clinicians wasting time in futile efforts to do so. Instead, the thesis casts ‘non-adherence’ as only one possible framing of the phenomenon of people not taking prescribed medication, and situates the initial research question within an exploration of the way people who are offered statins come either to take them or to decline them. This exploration has two aims. First, I seek to deepen understanding of medication decisions, and of the articulations between decision making and material medication practices. Second, by focusing on decisions about statins, I aim to shed light on the multiple discursive framings that inform decisions about preventive medication. I foreground the moral tensions people negotiate to legitimate medication practices regarding these particular medications, negotiations that are shaped by discourses concerning health promotion, medicalisation and risk.

The project which eventually evolved generated a detailed picture of the way people come to take regular medication. While statin decisions no longer dominate this picture, they remain a prominent feature. Statins typify a group of medications prescribed for people who feel well, in order to reduce the risk of illness in future. They are a class of drug that reduces cholesterol levels by inhibiting a liver enzyme essential for cholesterol production, and have been recommended increasingly widely in the thirty years since the link between high cholesterol levels and heart attacks was established. A recent



meta-analysis [Mihaylova et al, 2014] produced evidence that taking statins reduces the risk of cardiovascular events and has a very low risk of causing side effects. This evidence informs current guidance from the UK National Institute for Health and Care Excellence (NICE) that statins should be recommended to people whose risk of cardiovascular disease in the next ten years is above 10% [NICE 2014]. A recent Lancet review [Collins et al, 2016] reinforces this recommendation, describing the increased prescription of statins as a virtually harmless and highly cost effective strategy that would ‘prevent major vascular events from occurring’ in a significant proportion of the population. Yet prescribing and taking statins remains highly controversial. Within the medical community, the editor of the British Medical Journal has repeatedly questioned the robustness of claims about statins’ benefits and harms, and she responded to the Lancet review by calling for an independent review of the evidence to resolve ‘this increasingly bitter and unproductive dispute’ [Godlee, 2016]. Discussion about statins continues in the lay press, too: the medical controversy about more widespread statin prescribing has become a news item in itself, while articles with headlines such as ‘A nation of pill-poppers?’ indicate broader concerns about medicalisation. The role of health policy makers is also highlighted; in a UK broadsheet this summer, for instance, one article reported the NICE guidance under the heading ‘Millions more patients should be given statins, orders NICE’, suggesting unease about a population based approach through which ‘NHS watchdogs’ [sic] are cast as seeking to regiment medical treatment.

This outline of the recent debate about statin prescription illustrates that general practitioners (GPs), the main prescribers of statins in the UK, are advising patients against a backdrop of ongoing controversy. The controversy is not solely focused on assessments of the risks and benefits of therapies such as statins; it draws in wider social and cultural issues about the meanings of medications, medicalisation and the relationship between population benefit and individual choice. It is in this context of cultural unease that GPs are enjoined to help patients make decisions about preventive medication, providing them with evidence-based information and encouraging them to use this information in making a rational choice. My thesis problematises this injunction to clinicians; I demote rational choice to a supporting role within an account of the practices through which people legitimate and enact longterm pill taking, and foreground the discursive framings that shape these practices.

In this introductory chapter I review some of the literature on preventive medication and on how patients make decisions. The first section outlines the extensive bodies of research and debate within both biomedicine and social science about the dilemmas posed by prevention. In the second section I review the several different literatures that focus on patients' decision making. These preliminary literature reviews are complemented and extended throughout the thesis; within each chapter, I draw on other aspects of the sociology of health to relate my findings to what is already known.

### **Preventive medication: debates and dilemmas**

The way people decide about longterm preventive medication matters because prevention matters – there is a lot of it about – and because medication and other individually targeted preventive interventions are widely researched and promoted. The range of possible interventions is likely to expand dramatically over the next decade in the wake of a big expansion in the range of genes identifiable as conferring an increased risk of future disease, and a parallel increase in the range of affordable tests for these genes. New ways of identifying risk are often closely followed by the development of potential risk-reducing interventions to offer to those identified by these new screening techniques. In the context of genetics, the articulation between screening and treating is illustrated by the case of the BRCA mutations: currently, only people with a strong family history of breast or ovarian cancer are tested for these genes, and NICE currently recommends offering preventive medication or surgery to a small group of people identified as being at very high risk [2013], but this is likely to change as the cost of testing falls; Levy-Lahad et al [2015] argue for extending BRCA screening to the whole population, which would obviously enlarge the group of people offered preventive interventions.

While population screening and individually targeted risk reducing interventions are still a few years ahead in the context of most genetic risks, screening and interventions for increased cardiovascular risk are already well established, making statins (a purely preventive intervention used to reduce cardiovascular risk) a useful case study from which some conclusions may be generalisable to other contexts. The evidence presented and discussed in later chapters is situated against a backdrop of discourses about prevention in general and statins in particular, in which those originating within the

biomedical community are highly salient, so an account of these biomedical discourses is a good starting point.

### **Prevention from a biomedical point of view**

Prevention is ubiquitous in health policy documents as a desirable goal. In England, for instance, National Health Service (NHS) chief executive Simon Stevens devotes a chapter of his NHS Five Year Forward View [2014] to prevention, identifying it as a key element of his plans for the service. Both biomedical and lay writings frequently echo the common saying that ‘prevention is better than cure’; this often seems to go without saying, but is sometimes justified on financial or humanitarian grounds, as illustrated by a recent article by Savill et al [2015]. Within Stevens’ chapter on prevention, his emphasis exemplifies a move that is slowly gathering momentum in such documents: he gives much more space to population based interventions than to individually targeted ones. These two types of intervention are used side by side in the context of smoking, for example, tackled in the UK in recent years both by interventions such as legislation to restrict smoking in public places and by various programmes which identify individual smokers and seek to help them quit. As well as distinguishing between individual and population based interventions, a further, tangential dimension is sometimes considered in debates about prevention, situating interventions along a spectrum between those that benefit passive subjects and those whose benefit depends on active involvement. The passive end of this spectrum of interventions is exemplified by reducing the sugar and fat content of foods, and by bariatric surgery. The active end is exemplified by providing playing fields, and by encouraging individuals to take more exercise. The moral discourses that inform this active-passive dimension, and its effect on how people decide about statins, are central to the discussion in Chapter 5.

Individually targeted interventions have been criticised as likely to be less cost effective than population focused ones [Barry et al, 2015], and as tending to increase inequity [Nettleton and Bunton 1995]; Marteau and Kinmonth [2002] point out that even at the stage of screening or case finding (the first steps in programmes offering individual interventions), uptake is likely to be higher amongst populations at lower risk, ‘the worried well’. These critiques support policies that direct public health spending towards population based strategies. Alongside such strategies, however, the NHS still

promotes individually targeted interventions to deal with many public health problems. In the context of cardiovascular disease, for instance, the Health Checks programme [Department of Health 2014] screens individuals in order to offer advice and support about diet and exercise for individuals identified as having a suboptimal ‘lifestyle’, and to offer preventive medication such as statins and blood pressure pills to those whose risk of cardiovascular disease is above an agreed level. Criticism of this programme [Capewell 2015] centres on its low cost effectiveness, ascribing this to two factors: first, the low prevalence of people with modifiable risk factors within the population that is offered screening, let alone in the population likely to accept it; and second, the small number of those treated who benefit from risk reducing interventions relative to the number of those harmed by the interventions.

This second consideration, the net benefit, is particularly relevant to my thesis, requiring consideration of benefits and harms separately. Regarding benefits: statins are prescribed purely to reduce the risk of harm from cardiovascular disease. There is a broad consensus within the biomedical community that they do reduce this risk [Mihaylova for the Cholesterol Trialists, 2012], although the extent of the reduction is the subject of ongoing debate, with most arguments on both sides emphasising distinctions between different kinds of people; the two most prominent typologies distinguish between people who are known already to have cardiovascular disease and people who are not (offering interventions to these two groups is described respectively as secondary and primary prevention), and between people older or younger than various arbitrarily specified thresholds. Ethnicity is the basis of a third typology which is growing in prominence (as pointed out by Mathur et al [2011] for example), driven by differences in cardiovascular disease incidence between different ethnic groups. For the argument pursued in the thesis, these typologies raise interesting questions but are side issues; the crucial point about the benefits of statins is that an individual can never know whether or not she has benefitted from taking them – even if she never gets any illness related to cardiovascular disease, surviving to die of something different, she cannot tell whether she would have done so anyhow without the statins. This is true of all individually targeted preventive interventions, and might appear to offer a clear way to distinguish these from interventions classed as treatments: you can tell whether or not a treatment has worked. However, this distinction turns out to be intractably fuzzy, a claim grounded in evidence that I present and discuss in Chapter 4.

In the case of statins, the distinction between prevention and treatment is clouded by the widespread perception both inside and outside biomedical circles that the aim of prescribing statins is to reduce cholesterol levels. The obvious fact that cholesterol levels are a surrogate end point, and only matter because of their association with cardiovascular risk, is highlighted by evidence suggesting that the beneficial effect of statins on cardiovascular risk is not mediated simply by lowering cholesterol, particularly in the context of primary prevention: statins reduce cardiovascular risk even when they do not reduce cholesterol levels, while other drugs such as ezetimibe do lower cholesterol but do not reduce cardiovascular risk. This evidence against a pivotal role for cholesterol lowering informs the recommendation implicit in clinical guidelines on when and how to use statins, such as the one issued for the NHS by NICE [2014]: in the latest version of this guideline, the algorithms use quantitative estimates of cardiovascular risk as thresholds for intervention, with very few mentions of cholesterol levels. The guideline does nonetheless include a recommendation to monitor cholesterol in people taking statins, but states that this is in order to encourage them to keep taking the tablets; the old recommendation that prescribers of statins for primary prevention should ‘fire and forget’, rather than using ongoing cholesterol monitoring to ‘treat to target’, was debated a few years ago, for instance by Donner-Bantz Hof and Sönnichsen [2008], before fading quietly from the view of the non-specialist clinicians who do most of this prescribing and constitute the principal audience for the guideline. For these clinicians, the guideline tends to strengthen the focus on cholesterol by placing ‘Lipid modification’ at the beginning of its title, hence reinforcing a framing of statins and ‘lifestyle modifications’ as treatments for a lipid problem rather than as preventive measures aimed at reducing the risk of future harms. Beyond the biomedical community this framing is widely visible in the prominent reification of cholesterol as undesirable, something to be kept down by ‘healthy lifestyle’ choices or medication.

Some of the opposition to widespread use of statins is based on the evaluation that, at least in ‘low risk patients’, the likelihood of benefit is too low to justify their use. This stance, exemplified in an article by Abramson et al [2013], rests on the argument that too many people must be treated in order to save one person from having a heart attack or stroke. However, individuals offered statins may disagree with these value judgements about what constitutes a ‘low risk’ and the maximum acceptable ‘number needed to treat’. The value ascribed to avoiding a heart attack or to avoiding taking

longterm medication can be determined in two ways: either by the preferences of an individual, or by the cost-benefit calculations of a health economist considering both financial and QALY (quality adjusted life years) information about the population as a whole. In the case of statins, NHS guidance is primarily informed by a calculation that offering statins at a relatively low threshold of risk is cost effective, particularly now that most statins are cheap.

Complementing arguments centred on the low likelihood of benefit, criticism of the promotion of statins also highlights the likelihood of harm, particularly physical side effects. Abramson et al [2013] claim that these side effects are under reported in studies such as those included in the Cholesterol Trialists' meta-analysis [Mihaylova 2012], which has informed subsequent guidance on using statins [NICE 2014, Collins et al 2016]. The discrepancy between a widespread perception that statins often cause adverse effects, such as muscle pains, and the reported evidence to the contrary has led commentators such as Parish et al [2015] and Godlee [2016] to call for closer scrutiny of the way such evidence is generated. This is a topic beyond the scope of this thesis, except that in later chapters I use interview data about side effects to illustrate my methodological approach; highlighting the pitfalls of using reports of side effects as the basis for simple inferences about people's experiences, I identify the analytic advantages of a nuanced understanding that recognises the way such reports are used within accounts that legitimate participants' medication practices.

As well as this focus on physical side effects, increasing attention is paid to other potential harms of individualised preventive interventions like giving people statins. In order to implement the recommendation to increase statin prescribing, clinicians need to identify an increased number of people to offer statins to. For people who have not yet suffered any illness related to cardiovascular disease, eligible subjects for primary prevention, this identification process involves being labelled as 'at risk'. For people who have had a heart attack, recommending longterm medication for secondary prevention helps frame them as people with a chronic medical condition, ischaemic heart disease, replacing the old notion of making a full recovery. In the biomedical literature the net benefit of secondary prevention is largely unquestioned, at least in the context of cardiovascular disease, but concerns about the labelling involved in primary prevention have become increasingly visible in the last decade. For instance, writing in *The Lancet*, Gervas, Starfield and Heath [2008] include 'turn[ing] people into patients'

in their list of the undesirable effects of screening and individualised preventive interventions, alongside more pragmatic drawbacks like exposing more people to the risk of side effects and diverting clinicians' time and energy away from attending to ill people. Moynihan et al [2012] give the same list of drawbacks in an article about 'overdiagnosis' that begins by stating that 'medicine is harming healthy people through ever earlier detection and ever wider definition of disease'. Their article invites doctors to attend a conference about 'Preventing Overdiagnosis'; this now annual conference is part of one of several similar campaigns to emerge recently in high income countries, with medical journals presenting debate under headlines such as the BMJ's 'Too much medicine' [Moynihan 2013] and JAMA's 'Less is more' [Redberg 2010].

Within these 'overdiagnosis' debates, the topic most directly relevant to my research is the growth of screening. In the words of the UK National Screening Committee [2016], screening is done to 'apparently healthy' people; it has the effect of labelling some of these people either as having a disease of which they have not yet experienced symptoms, or as at high risk of future illness. Aronowitz [2009] writes about the convergence between the experience of having a 'symptom-less and sign-less disease' and the experience of being identified as 'at risk for disease'. This convergence in patients' experience reflects a widely visible biomedical discourse that valorises both early detection and aggressive treatment of 'risk factors' such as raised levels of cholesterol or blood pressure; it is this discourse that the various 'overdiagnosis' movements are challenging. The distinction between the enterprise of screening and the enterprise of diagnosis depends not on their products – the labels produced by screening are not neatly distinguishable from the labels produced by diagnosis – but on how people come to be subjected to labelling: screening is done to a person who is not aware of any problem, whereas diagnosis is done to a person who seeks medical advice about a concern which is then labelled as a medical problem. A possible grey area between these two enterprises has been created by the introduction into health policies and clinical guidelines of a new term, 'case finding', but conceptually this is just a subset of screening: screening looks at a large proportion of the population, such as all women or middle aged people, whereas case finding looks at a smaller proportion, such as all older people with cardiovascular disease. Both these kinds of target group comprise people who have not raised any concerns relevant to, say, cervical cancer or dementia. A recent recommendation about case finding for dementia in the UK appears to have

been a (not very successful) device to circumvent clinicians' opposition to a possible new programme of dementia screening, as McCartney [2014] points out.

Such opposition indicates increased awareness amongst doctors of some of the negative unintended consequences of the pursuit of prevention. This increased awareness is one element of a broader change within the biomedical community: there is a growing reflexivity about the tension between the mainstream account of medical advances or medical progress, terms which clearly indicate a positive framing, and medicalisation, a word invariably carrying negative connotations. I return to discuss this tension in several chapters of this thesis, foregrounding it particularly in relation to participants' accounts of their medication practices in Chapter 5 and in relation to debates about evidence based medicine in Chapter 8. An extensive social science literature informs these discussions. While each of my chapters includes an account of relevant parts of this literature, I provide an introductory outline here, summarising debates about medicalisation and risk that underpin the sociologies of diagnosis and screening.

### **Screening and diagnosis: constructing 'being at risk'**

In the previous section, writing from a biomedical perspective, I have characterised the direct effect of screening as 'identifying' individuals whose risk is deemed high enough to treat, a characterisation that implicitly casts risk levels as features of a body that has a real, stable existence. This positivist stance is problematised within an extensive body of sociological research and debate about screening and risk; the following brief overview places David Armstrong's work at its core.

In an article that identifies the limitations of accounts of health and illness centred on a constant 'biological body', Armstrong [2012a] discusses the advantages of adopting an alternative, socially constructed model he terms Durkheim's body. Rosenberg [2002] sets out a similar argument in his essay about the close articulations between diagnosis and disease; examining the way that the process of diagnosis 'helps constitute and legitimate the reality that it discerns', he emphasises that diseases and diagnostic categories are inherently unstable, rooted in diagnostic framings and processes that change over time. Like Armstrong, Rosenberg questions the explanatory power of conceptualising disease entities as 'mirrors of nature'. His account of the evolution of the process of diagnosis over the last two centuries echoes many of the points Armstrong makes in an earlier book [1983]. Both these authors, then, make a cogent



case for an ontological approach that frames health and disease as situated phenomena, shaped and made visible by the practices of medicine.

Armstrong's book [1983] describes a collection of closely interrelated changes as transforming the remit and character of medical practice during the 20<sup>th</sup> century, illustrating his thesis mainly with examples of practice in the UK. Building on Foucault's account of disciplinary power, Armstrong chronicles the expansion of the medical gaze to focus not just on individual sick patients but on the whole population. He discusses a related shift in the way the medical gaze functions, a shift that has reconceptualised and problematised normality. In this shift, 'a central element...[was] the rejection of "the norm" and the focus on "normal variability"' [p34], a focus that informed the practices of surveillance. As Armstrong describes, these practices rapidly gained prominence and popularity during the last century. Rather than simply surveying this continuous variability, however, clinicians soon began to use it as a starting point for intervention; having 'uncovered continuity, [the survey] focused attention on the borderline between normality and abnormality' [p78]. This focus on the boundaries that delineate 'normality' is central to the construction of a growing group of entities that have come to be widely characterised as chronic medical conditions.

Hypercholesterolaemia and hypertension, two such conditions, are mentioned frequently in the data I present later in the thesis. Armstrong challenges the claim that the increasing prevalence and prominence of chronic rather than acute illness in the late 20<sup>th</sup> century mainly reflects 'technological advance and the elimination of acute infections'. Instead, he suggests that 'medical power has created a new domain of illness', a domain in which increasing numbers of people have a chronic medical condition or are 'at risk' of future illness.

Armstrong's detailed exploration is particularly helpful for understanding the shifts in power central to accounts of medicalisation, like the account that underpins Annemarie Jutel's [2009] review of the sociology of diagnosis. Like Rosenberg, Jutel makes the ontological point that, in the prevalent biomedical model, 'diagnosis brings conditions forward as "always-already-there objects in the world"'. She problematises this stance in an account of the evolution of disease classifications in which she foregrounds the way 'social elements influence and frame diagnoses, and lead decision makers to view a diagnosis as validating a reality which is simply waiting to be discovered'. In this 2009 article Jutel's explicit focus is on the work done by diagnostic categories, rather than on

the process of making a diagnosis. Her later article [2011] about the sociology of diagnosis, written with Sarah Nettleton, emphasises that although ‘the category and process of diagnosis are ... inextricably interlinked and mutually constitutive’, considering them separately is a useful analytic approach. Jutel and Nettleton use the distinction made by Blaxter [1978] between diagnosis-as-category and diagnosis-as-process. Examining the way doctors use a new diagnostic category, alcoholism, Blaxter concludes that ‘diagnostic activity’ is inextricably linked to medical treatment, and that therefore doctors may be reluctant to use a diagnostic category ‘for which no clear medical prescription exists’. Jutel and Nettleton broaden this concept of ‘prescription’, extending Blaxter’s heuristic by identifying ‘consequences of diagnosis’ as a third object of study. This extended heuristic is helpful for thinking about screening and comparing it with diagnosis.

In the account at the start of this chapter, I adopt a biomedical perspective to state that screening differs from diagnosis principally in respect of the processes involved; there is no clear distinction between the categories generated, or between the consequences of being given a label by being assigned to those categories. A key difference between the processes of screening and of diagnosis concerns the role of medical power. In both processes, medical authority pervades the interaction between a doctor and a patient, shaping both the stage where the doctor questions the patient or offers tests, and the stage where they explain their conclusions based on the resulting information. In the case of screening, however, a second kind of medical power is also visible upstream, shaping the context in which these individual interactions take place; health promotion, the broader enterprise of which screening is an element, may be seen as a governmental technology.

An extensive literature examines and critiques health promotion from a Foucauldian perspective. I return to these critiques in Chapter 5, relating them to my discussion of moral identity in the context of taking statins. In this introductory chapter, I give a few examples that illustrate the way the health promotion literature informs my understanding of screening and risk. Turner [1987] explores the tension between two explanatory approaches used for understanding the changing landscape of health and disease over the past few decades: he compares Foucault’s ‘analysis of power/ knowledge/ discipline (namely “governmentality”)’ with Beck’s ‘risk society’, identifying Foucault’s approach as central to the construction of a sociology of health

that 'contribut[es] to the study of ... micro-practices of power'. Crawford [1994] foregrounds the normative character of these micro-practices; tracing the construction of the "at-risk" self, he describes the conversion of 'the healthy individual... into a person who is potentially sick', asserting that 'health continues to be a moral discourse'. Lupton [1997b] discusses the way a disciplinary power shapes what Foucault termed 'practices of self', informing responsabilising health promotion discourses through which 'people are constantly urged to conduct their everyday lives in order to avoid potential disease or early death'. These discourses are clearly visible within two overlapping enterprises, screening and promoting early diagnosis; both attending screening tests and reporting 'potentially worrying' symptoms are widely framed as sensible elements of maintaining one's own health. In their overview of sociological studies focused on screening, Natalie Armstrong and Helen Eborall [2012] cite research about cervical screening, both to highlight the role of responsabilisation as a driver of screening attendance and to illustrate some of the broader questions that screening programmes raise.

Screening is a topic particularly pertinent to my research; to understand how people decide whether to accept statins, it is important to understand the process through which most people come to be offered preventive interventions, and to build a clear account of the way they use information from their screening tests. David Armstrong [2012b] traces the evolution of screening, identifying it as 'a key component of [the] wider strategy' which informed the project of prevention that took shape in the 20<sup>th</sup> century. This project was predicated on 'a vision of numerous disease timelines which could be targeted at any point so that subsequent illness could be forestalled'. Armstrong identifies two roots of the term 'screening' that remain visible within the enterprise of screening as it is pursued in the 21<sup>st</sup> century. One of these roots, the use of X-rays to look for early signs of tuberculosis, can be recognised in screening programmes whose aim is framed (by doctors and patients) as early detection, identifying an existing condition that is problematic in its own right from a medical perspective because of the risk that it will worsen and cause illness. Breast screening exemplifies this. Armstrong portrays the other historical root of screening as analogous to the use of a mesh or sieve to pick out one subgroup of a population, separating its members from other people on the basis of a parameter that varies continuously within the population. For example, the biomedical definition of hypertension rests on a line on the bell curve that describes

blood pressure variation within the population; if the average of an individual's repeated measurements lie above that line, then they are diagnosed as having hypertension. 'Well person checks' that include measuring blood pressure exemplify this second kind of screening. However, the usefulness of this appealing historically rooted typology is limited by adopting Armstrong's own constructivist stance: the distinction rests on the characterisation of breast screening, for instance, as surveying a binary characteristic as opposed to a continuum like blood pressure, but evolving investigation technologies increasingly blur the line between having cancer and not having it. This exemplifies the phenomenon Rosenberg [2002] refers to as 'the iatrogenesis of nosology', describing 'our increasing ability to create and modify disease entities' and thus complicating the notion of 'a condition', a notion I examine and discuss in Chapter 4.

Armstrong's [1995] account of 'Surveillance Medicine' sheds light on the ways disease entities may be created and modified. Armstrong casts Surveillance Medicine as an extension of Ackerknecht's and Jewson's widely cited accounts of a series of 'distinct medical perspectives' succeeding one another over recent centuries: he tells the story of the expansion from a two dimensional Bedside Medicine, concerned with the patient's symptoms and typically situated at home, to a three dimensional Hospital and Laboratory Medicine, situated in hospital and concerned with an underlying pathological condition indicated not only by symptoms but by physical signs and laboratory tests. Armstrong adds a new chapter to this story, building on Foucault's [1973] account of the spatialisation of illness. Surveillance Medicine involves expanding this spatialisation along two different axes, one contextual and the other temporal: as well as screening large groups of people rather than looking at one individual at a time, surveillance extends medical attention and influence beyond current health problems to include possible future harms and benefits. These two expansions articulate with one another to make preventive interventions possible; population based information is used to calculate the likelihood of future events and relate this likelihood to factors that can be assessed in the present. Thus, for an individual who feels well at present, the advantage of undergoing screening is that it may identify a high risk of future illness and that this risk may be reduced by a preventive intervention.

This formulation of the consequences of screening highlights the uncertainty inherent in all aspects of the enterprise. Uncertainty is an inescapable feature of the information

generated by screening processes, resulting from both the kinds of expanded spatialisation Armstrong highlights. The contextual expansion of the medical gaze assumes that credible inferences may be built about an individual by using knowledge about a population. I problematise this assumption in my discussion of evidence based medicine in Chapter 8, emphasising that the applicability of general information to a particular case is irreducibly uncertain. Expansion of gaze along the temporal axis, both its past and its future portions, is considered in Chapter 4, where I explore the role of certainty and uncertainty in accounts of medication decisions and argue that the cogency of information about risk is reduced by the uncertainty that characterises any information about the future.

Information about risk, and how best to communicate it to patients, are central concerns within many of the literatures about health decision making that I review later in this chapter. In the medical literature, a dramatic increase in prevalence of the word 'risk' in recent decades is described by Skolbekken [1995] as a 'risk epidemic'. To understand this epidemic, Skolbekken considers two ways in which the word 'risk' is used; his first category, illnesses seen as caused by the health care system, is not directly relevant to my thesis. Skolbekken's second category concerns 'risk factors'; drawing attention to the rapid growth within the biomedical community of interest in factors that make illness more likely, he points out that 'the identification and estimation of risk factors' is one of the main objectives of screening and a key element of many health promotion strategies. Complementing Skolbekken's discussion of the role that the concepts of risk and risk factors play in medical discourses, Davison, Davey Smith, and Frankel [1994] examine the way these concepts are used in data from interviews with lay people about coronary candidacy. As well as referencing extensive knowledge about the factors that doctors say increase the risk of heart attacks, Davison et al's participants indicate awareness of the weakness of risk factor information as a basis for predicting who will have a heart attack in future. Given this awareness, one might expect that personal risk factor information would have little effect on the person given it, but a large body of evidence contradicts this. My thesis builds on and contributes to two aspects of this evidence: I examine the way risk information is used in accounts of medication decisions, and I describe the reification of risk factors such as cholesterol, which participants talk about as a current problem that needs treatment.

The effect of being told one is 'at risk' is explored by Scott et al [2005]. Drawing on data from interviews with people who are attending a genetic assessment and counselling clinic because they have a close relative with cancer, they examine the way participants talk about the individualised risk information they have been given, information that incorporates the results of genetic tests. Scott et al report that these participants 'tend to see themselves in a liminal position betwixt the healthy and the sick'; the screening process has conferred a new 'at risk' identity. The current rapid increase in the potential to identify risk-conferring genes is likely to produce an expansion of Skolbekken's 'risk epidemic' that will be widely visible outside as well as inside medical journals. In the context of this rapid expansion, a question Scott et al raise seems particularly pertinent: should they refer to their participants as 'patients' or as 'clients' of the genetic clinic? Studies of people who receive different, non-genetic kinds of 'at risk' diagnosis through screening strongly suggest that the recipients of such labels cast themselves as patients. In work on osteoporosis screening, for instance [Reventlow, Hvas and Malterud, 2006; Salter et al, 2011; Skolbekken, Osterlie and Forsmo, 2012], women told that their bone density is below an acceptable level reify this test result, talking about it as a problem in its own right. These findings illustrate the way that a screen-detected risk factor has come to be framed as a medical condition meriting intervention. Whether this intervention is framed as 'treatment' or 'prevention', and relatedly, whether the condition is framed as a current problem or as a state of increased risk of future problems, are key questions addressed in this thesis, because they are key to understanding the way people assess their health and make decisions about health behaviours such as taking medication.

## **Health decision making**

It is almost forty years since the World Health Organisation, meeting at Alma Ata, declared that 'people have the right and duty to participate in the planning and implementation of their health care' [WHO 1978]. Over those years, patient involvement in making decisions about their medical care has become a universally accepted objective at every level of many healthcare systems, from policies to clinical consultations. At the policy level, in the UK for instance, patient empowerment is the topic of a section of the NHS' recent Five Year Forward View [Stevens 2014] stating that giving patients information and enabling them to make choices are key goals. At

the clinical level, a shared decision is the objective of the consultation in models such as the Calgary Cambridge one [Kurtz et al, 2003], widely used in teaching and training clinicians.

Embracing patient choice as a goal challenges the traditional paternalistic relationship between doctor and patient, potentially recasting the patient as a consumer of health care. Angela Coulter, who has written extensively about shared decision making, discusses this changed relationship; her account [1997] foregrounds the importance of providing patients with information, emphasising that shared decision making ‘requires shared access to the evidence supporting clinical decisions.’ Shackley and Ryan [1994] adopt a broader perspective in their analysis of increasing consumerisation of healthcare, which they describe as an implicit goal of late 20th century NHS policy; they focus on the doctor-patient relationship and the extent to which patients want and can have the agency implicit in the concept of a ‘good consumer’ of healthcare. Much of their discussion concerns the role of this hypothetical consumer in the context of choices about healthcare provision, but their account of a growing emphasis on patient choice and autonomy is equally pertinent to decisions about individual treatment; to illustrate this emphasis, they cite a UK government document in 1991, Health of the Nation, which calls for action to ‘ensure that people are properly informed and have the freedom to exercise choice’. These two elements, ‘proper’ information and freedom of choice, are problematised in the two discussion chapters at the end of the thesis. Both elements remain highly visible in 21<sup>st</sup> century health policy, and within research and debate generated by the several academic disciplines interested in health decision making. This large body of research and debate is underpinned by assumptions about what counts as ‘proper’ information, and about how choice is enacted, and these assumptions raise broad questions about power: who gets to rank different kinds of information? And what constraints is choice supposed to be free from? Despite this common ground there is little apparent interaction between the different literatures; authors writing about health literacy, medical decision making, and shared decision making cite one another’s work surprisingly seldom, so their approaches are described separately here.

## **Health literacy**

The central objective of promoting health literacy is to make biomedical information intelligible to patients; Charles, Gafni and Whelan [1999] characterise this objective as enabling doctors to fill patients with new knowledge, thus treating them ‘like an empty glass’. This could be said to overstate the case against it, since for instance Protheroe, Nutbeam and Rowlands [2009] emphasise a dual objective: as well as making information clear and comprehensible, practitioners should give patients ‘empowering’ education and support, providing them with skills and confidence to make use of their new knowledge. There are two problems with this recommendation, one practical and one ethical or political. The practical problem is that even skilled, confident patients may not actually use information in making health decisions. Gale et al [2011] found that they did not, in a trial of an intervention in which participants were taught how to understand their personal risk estimates before being given them: despite demonstrating during the intervention that they understood this information, very few participants used it in deciding whether or not to take statins, instead preferring to ask their doctor’s advice.

The ethical problem with the enterprise of health literacy concerns the tacit assumption that some information and ways of deciding are more worthy and valid than others. This assumption is indicated by some of the data Barry et al [2000] present, from a qualitative study of communication within GP consultations. Drawing on Mishler’s account [1981, in Barry et al] of the two different voices in which patients communicate, one inside and the other outside the consultation, the authors highlight the tendency for both doctors and patients in their study to rank ‘the voice of medicine’ above ‘the voice of the lifeworlds’. Barry et al point to some possible drawbacks of this tendency, and propose ways in which doctors might elicit patients’ unvoiced agendas. Their goal is to make consultations more patient centred and hence, they suggest, more effective. In contrast, Protheroe et al [2009] relate their advocacy of improved health literacy to a different goal, stating that health literacy is ‘a necessity for increasing participation in health care’. Describing a patient as ‘functionally “illiterate” when required to comprehend and respond to unfamiliar vocabulary and concepts in an unfamiliar environment’, Protheroe et al point to the need to address this defective literacy, which is cast as a barrier impeding equitable distribution of the benefits of



increased participation. To overcome this barrier, the authors suggest public education projects, and recommend that a doctor should assess their patient's literacy and work to improve it. This framing explains communication difficulties primarily in terms of patients' deficiencies, reinforcing a tacit hierarchy in which medical advice ranks above patients' own knowledge and the biomedical discourse is privileged over its rivals, a hierarchy that is also visible in the literature centred on medical decision making.

### **Medical decision making and adherence**

Much research about medical decision making is rooted in behavioural science. Reyna [2008] describes its approach as constructing models which predict how people behave, and using these to suggest ways to influence behaviour with the aim of improving health outcomes. Adherence is typical of the kind of behaviour one might attempt to influence; from a biomedical perspective, low adherence to long term medication, for instance, is a frustrating obstacle to improving health and thus widely cast as a problem. For instance, Haynes et al [2008] review interventions that aim to 'improve' adherence, and point out that the low effectiveness of currently available interventions prevents 'the full benefits of treatment [from being] realized'. Although this review mentions that demonstrable improvement in treatment outcomes was rare, even with interventions which did increase adherence, the assumption that more adherence is better is not problematised. This assumption underpins accounts of 'barriers to adherence' such as McHorney and Spain's [2010], which distinguishes perceptual, intentional barriers from practical, non-intentional ones. Proposing a 'necessity: concerns framework', Horne and Clatworthy [2010] describe people as tending to weigh up barriers to taking medication against reasons in favour of taking it, and express the hope that understanding the origins of 'doubts about necessity and concerns about potential adverse effects of treatment' will help clinicians to identify and challenge these barriers in their patients.

Although these behavioural scientists give examples of barriers (particularly of the 'practical' type) situated away from the clinical setting, their primary focus remains upon the clinical consultation where the treatment plan originates. This is illustrated by Spring's [2008] account: she draws attention to the distribution of decision making with respect to time and space, stating that 'patients are continually and in real time making lifestyle decisions', yet frames this primarily as a challenge for the clinician to overcome. Spring's expressed objective is a theory to help explain 'how to make the

provider-patient collaboration stickier’, so as to help doctors to cause patients to keep making ‘healthful decisions’ in between consultations; such a theory implicitly leaves the clinical encounter at the centre of the project of improving decision making, and gives the clinician the power to evaluate and rank the collection of information and concerns which define a decision as ‘healthful’. This does not appear to be a ‘collaboration’ between equals; like in the literature about health literacy, tacit assumptions about information and power are visible here, too. A hierarchy of reasons to decline medication is indicated by accounts implying that evidence based medical advice is more valid than what McHorney and Spain describe as *fear* of side effects and ‘lack of *perceived* need’ (my italics); by framing these as ‘perceptual’ barriers to medication they suggest a tacit contrast with *real* barriers. Similarly Horne and Clatworthy’s plan to challenge patients’ doubts and concerns seems to rest on the assumption that, once their origins are ‘understood’, these implicitly soft barriers can be overridden by arguments based on solid biomedical facts.

This hierarchy of kinds of knowledge informs a hierarchy of decisions which is at odds with the widely proclaimed high regard for patients’ freedom to choose, as Horne and Clatworthy indicate by specifying that their primary goal is facilitating ‘informed adherence’ to the plan recommended by the clinician. The tension between this goal and the goal of facilitating shared decision making is illustrated by the controversy about a decision aid intended to help people decide about a screening programme for bowel cancer. An evaluation [Smith et al, 2010] found that using the decision aid increased participants’ knowledge and made them more likely to make an informed choice, but it made them less likely to opt to undergo screening. Commenting on these findings and on the authors’ conclusion that the decision aid should be adopted, Bekker [2010], a behavioural scientist, wrote that ‘uncritical acceptance of informed choice initiatives may cause more harm than good’. She suggested that the decision aid should be replaced by an alternative that would ‘structure the facts ... to facilitate adherence with testing – that is, a policy of informed uptake rather than informed decision making.’ These suggestions elicited a collection of strongly critical responses; Penston [2011] later accused the UK National Screening Committee of ‘using propaganda to promote screening programmes’. Thus the different disciplines within which health decisions are studied do not simply work in parallel; in some respects they rival each other, in clashes rooted in differences between their aims. These aims inform the different ways a

decision is evaluated within different research communities: behavioural scientists evaluate the content of a decision, using what they perceive to be the right answer as their yardstick, whereas those who study shared decision making have moved away from this yardstick in recent years, replacing it by evaluating the decision making process. I describe this move in the next section, and later explore it in more depth in the discussion of evidence based medicine in Chapter 8.

### **Shared decision making**

Information and choice remain centre stage in accounts of shared decision making such as those by Charles and Gafni [1997] and Charles, Gafni and Whelan [1999]. But unlike the approaches described above, the project of shared decision making is unequivocally situated within the clinical consultation, with collaboration as a goal in its own right. This project is informed by two discourses, patient centred care and evidence based medicine, each the subject of an extensive literature. Shared decision making is a central character in both these literatures; for example, Little et al [2001] say that a partnership approach is a key domain of patient centred consulting, and popular with patients, while improving clinicians' skill at facilitating shared decision making is one of the recommendations made by Greenhalgh, Howick and Maskrey [2014] in their call for a new 'real' evidence based medicine. The potential tensions between patient centred and evidence based medicine are discussed by Gupta [2011], who points out that they inform two different ways of evaluating a decision: a good decision may be one that the patient is comfortable with, or it may be one that incorporates the best available evidence relevant to her particular case, and the two do not necessarily coincide. This possible discrepancy is acknowledged within the shared decision making literature, for instance by Edwards and Elwyn [2001], who state that informed choice should be the preferred goal of clinical consultations even where this conflicts with maximising health gains. Edwards' [2003] account of 'informed dissent' highlights this conflict. In the example described above, where information about bowel screening was the subject of heated discussion, Edward's own stance informs Smith et al's [2010] assessment that the decision aid was a success, and he explicitly rejects the stance illustrated by Bekker [2010] that casts population health gain as the primary goal of interventions which aim to affect decision making.

The emphasis on shared decision making as a collaborative endeavour, with clinician and patient each bringing their own knowledge to ‘a meeting of experts’ [Tuckett et al, 1985], might suggest that this meeting takes place on a level playing field, but there are several ways in which the interaction is inherently asymmetrical. Power is asymmetrical in three overlapping aspects of the decision making process: knowledge carries more weight within the process than individual feelings and values; different kinds of knowledge are accorded differing amounts of respect; and the process itself is evaluated on a yardstick which equates rational deciding with good deciding. These asymmetries are all visible in a comment in Elwyn and Miron-Schatz’s [2009] article about shared decision making, that ‘decisions made without any information whatsoever are mere guesses’. The implicit idea of an information vacuum only makes sense given a narrow definition of information, similar to the definition Charles, Gafni and Whelan [1999] indicate in their reference to treating the patient ‘like an empty glass’ into which useful medical information can be poured. Elwyn and Miron-Schatz’ comment gives no indication of a cogent role for values and feelings alongside information in making decisions; a ‘mere guess’ is presumably the antithesis of a rational cognitive process for which, the authors state, it is sufficient for the clinician to give the patient an awareness of options to choose between plus at least a small amount of information.

### *Information versus feelings*

The ranking of information above feelings and values is often invisible in accounts of shared decision making; for example, in presenting a new tool for assessing decision aids, Elwyn et al [2009] state that these aids must ‘help clarify personal values’, and then factor them into the recommended decision alongside personal biomedical information and evidence based facts. It is clearly possible to devise algorithms which do accord these values the same weight as the evidence based information the patient is given, but there is a problem with the implied idea that personal values are fixed, context neutral objects waiting to be ‘clarified’, a problem which becomes particularly salient when considering encounters not between a person and an algorithm but between two human actors. In a clinical consultation, power asymmetry is visible in every aspect, from arranging an appointment to obtaining tests or treatments to which clinicians control access. In between these two bookends, the power to determine the content and process of the interaction is unavoidably asymmetrical too. This does not only apply to the decision making stage of the consultation; before any choosing can

begin, the doctor has the power to accept or deny the patient's implicit suggestion that their problem is a 'medical' one, and sometimes to strengthen this framing by labelling the problem with a diagnosis; Jutel and Nettleton [2011] quote Friedson's statement in 1972 about the process of diagnosis, that 'whosoever holds the power to control this process is ascendant'.

This work of defining the problem is inextricably linked with the work of trying to solve it, as Gwyn et al [2003] illustrate in their detailed account of a single consultation in which the doctor talks about heart risks while the patient talks about cholesterol. Gwyn et al point to the asymmetry indicated by the words used, with the doctor repeatedly speaking of his 'thoughts' and the patient's 'feelings'. Similarly, Pound et al [2005] problematise the way many biomedical policy documents refer to patients' 'beliefs' and 'abstract worries' about adverse effects of medication, directing attention away from these effects as a topic worthy of consideration in itself; they are critical of this framing, which they suggest is reinforced by sociological approaches that 'focus on "perceptions" of medicines or the "meanings" people attach to medicines', rather than on implicitly concrete objects such as the harms caused by medicines.

This criticism is echoed by Timmermans and Haas' [2008] call for a sociology of disease, particularly in their warning that a strong constructivist approach may unhelpfully limit sociologists' ability to explain what is going on. Yet a positivist stance obscures the fact that there is no tidy distinction between subjective feelings and objective knowledge; knowledge is constructed and used in ways that are value laden and context specific. Gupta [2011] helpfully identifies the weaknesses of evidence based medicine's claims to be value neutral, and two of the problems that Greenhalgh, Howick and Maskrey [2014] hope to solve with their improved new version of evidence based medicine are the difficulties of working out which evidence based facts are likely to be applicable to a given individual, and the challenge of making experiential knowledge a reliable and generalisable basis for decisions.

### ***Types of knowledge: experiential versus theoretical***

Another consultation studied by Gwyn and Elwyn [1999] highlights the gap between Tuckett et al's [1985] 'meeting of experts' and typical clinical practice: the context is the very common disagreement about antibiotics for a sore throat, a context in which widespread current recommendations dictate that, in Gupta's terms, the goal of

improved public health should take precedence over the goal of strengthening patient autonomy. Gwyn and Elwyn describe the way the doctor first elicits an account of the patient's own experiential knowledge, along with their concerns and their preference for antibiotics, then follows the evidence based guidelines and declines to prescribe antibiotics. The authors suggest that doctor and patient can be said to collaborate in decision making on a basis of shared acceptance of unequal power, since 'professional dominance is ... not contentious.' Gwyn and Elwyn's own agreement with this stance is underpinned by a tacit assumption that evidence based knowledge trumps experiential knowledge; the patient's experiential knowledge is referred to as 'their own "evidence"', constituted by 'the recall of prior experiences, anecdotes received from relatives and friends, the stream of often contradictory information from newspapers and television'. This knowledge, Gwyn and Elwyn explain, informs 'patient preference', which may conflict with 'the doctor's prescribing choice', words which again underline the patient's limited agency within the consultation.

The assumption that there is a simple relationship between the doctor's choice of action and her evidence based, theoretical knowledge is challenged by Gale, Marshall and Bramley [2012]. Drawing on qualitative evidence that they review and synthesise, Gale et al highlight the extent to which both clinicians' and patients' medication decisions about preventive medication are influenced by a wide range of factors including the perceived trustworthiness of sources of information, preferences for lifestyle changes over medication, and the extent to which the other demands patients face may take priority over taking medication. These are all factors I consider in this thesis. Gabbay and le May [2004] interview GPs in a study examining the way clinicians use information; they offer a detailed account of the way doctors construct and use 'mindlines', personal collections of working knowledge which incorporate their own experiential knowledge and the opinion of trusted colleagues alongside official evidence based guidance.

There is an interesting similarity between the constituents of these doctors' 'mindlines' and constituents of the "evidence" which Gwyn and Elwyn describe patients as amassing, a similarity which offers further support for the idea that only a very blurred distinction separates the kind of knowledge patients use in making decisions and the kind doctors use. This idea is useful in considering another feature of the shared decision making process highlighted by those who study it: the concept of equipoise.

Elwyn et al [2000] describe the view of a group of doctors that it is only appropriate to offer the patient a choice between alternative treatments in circumstance where the doctor believes both alternatives to be equally good, situations of ‘professional equipoise’. Elwyn et al do explicitly criticise this stance in a later paper [2003], stating that it is always appropriate to offer shared decision making because ‘patients have legitimate perspectives on many social and psychological aspects of decisions’, but it is not clear how these ‘perspectives’ are to be weighed against medical knowledge where the two point to opposite decisions. And despite Elwyn et al’s disapproval, the empirical evidence about doctors’ views in their earlier paper [2000] is echoed by the findings of Towle et al’s [2006] study of doctors’ accounts of their behaviour; as well as offering examples of situations such as emergencies, in which lack of equipoise precluded shared choosing, they reported that doctors decided which patients were suitable choosers. These decisions were informed by assumptions about the type of person likely to want to be given choices or to be capable of making them, assumptions which suggest a tacit hierarchy not only concerning the type of knowledge to be used in decision making, but also concerning different types of decision making process.

### ***Rational decisions versus ‘mere guesses’***

The evaluation that rational decisions are better than irrational ones is frequently surfaced by statements in the shared decision making literature, such as Elwyn and Miron-Schatz’ [2009] proposal that a shared decision making approach should be judged by its success at promoting ‘an effective deliberation process’. Such statements invite questions about what constitutes effectiveness, and several authors propose possible lists of desirable outcomes to use in assessing this. This focus on outcomes is particularly prevalent in discussion of the overlapping topics of decision aids and risk communication. Charles et al [2005] critique the large body of work that proposes outcome measures with which to assess decision aids, pointing out that this work often omits to specify the goals which the decision aid is being used to achieve, or to justify these goals in the context in which the aid might be used. This omission is exemplified in much of the extensive literature on risk communication, some of which is reviewed by Trevena et al [2006]; there is a strong focus on outcome measures concerning knowledge and understanding of ‘evidence’, justified as an end in itself by citing a General Medical Council statement that ‘moral, ethical and legal imperatives require patients to be informed by high quality information’. The possibility that patients might

decline to be informed is not mentioned, although a group of outcome measures concerning patients' feelings (such as satisfaction, anxiety or decisional conflict) are considered.

Instead of looking at outcome measures, Elwyn and Miron-Schatz [2009] suggest a different definition of a good decision, proposing that it is the 'deliberation process' itself which should be assessed. Their preference for deliberation over guessing is highlighted by the detailed scoring systems devised by Elwyn and colleagues [2003, 2009] to assess how well the process is carried out; these assessment criteria measure whether options are formulated and information is provided within clinical consultations [2003] and the extent to which decision aids [2009] 'provide structured means to help people deliberate', thus improving the quality of decisions. This account of improvement clearly equates rational decisions with good ones, and, like in the risk communication literature, there is no acknowledgement of the patient's right to choose not to deliberate. The right to choose whether and how to choose is implied in more recent work, however; for instance, Greenhalgh, Howick and Maskrey [2014] recommend that clinicians should establish 'to what extent, and in what ways, does this person want to be "empowered"?'

Leaving aside the GMC's moral, ethical and legal imperatives, the project of shared decision making is constrained in practice by two linked features which limit how much it can affect what people do: its focus on the consultation, and its framing of decision making as a cognitive process. Within the context of the consultation, the patient has little power either over the type of decision making process enacted or over the kinds of raw material incorporated into the process, and so her only absolute and direct power lies in saying 'No' to what the doctor offers her, either to involvement in the process or to the decision it produces. In contrast, as Pound et al [2005] point out, the doctor 'is oddly powerless once the person has left the surgery', and it is outside the surgery that most health decisions are either put into practice or set aside.

### **Distributed decision making**

Tim Rapley [2008] makes a helpful first step away from the focus of the standard shared decision making model on 'one-off dyadic encounters within the space of consultation rooms'. Instead, he proposes research into the way decisions get taken in a distributed way, spread across a variety of times and places and involving a variety of



people. This broader focus informs the research presented here, as it seems intuitively likely to shed light on the way people come to take statins at home every day for years, and perhaps also on the way others who are offered statins end up not taking them.

The need to look beyond the doctor-patient dyad when studying decision making is highlighted by Charles and Gafni [1997] and Charles, Gafni and Whelan [1999], and Rapley pursues this idea, offering an account in terms of decisions reached by interactions within ‘a web of intersubjectivity and relationality’, a condition he calls ‘relational autonomy’. Others (such as MacDonald [2002]) have traced the origins of this term to the writings of feminist scholars like Donchin [1995], who coined it to problematise the assumption that to be autonomous an individual must act independently. While the term ‘relational autonomy’ seems unsatisfactory because of an apparent internal contradiction, the concept is extremely useful, as Rapley demonstrates by drawing on several empirical studies. He highlights a contrast between two framings. In one, the patient is cast as an autonomous individual who must be helped to make up her own mind, a notion implicit within most biomedical writings about patient choice and shared decision making; in the other, she makes up her mind by talking with various other people. As well as people she knows and meets face to face, both at the doctor’s surgery and outside, she is likely to interact with those who write or speak in the media, nowadays particularly the internet, as many authors (for example Sillence et al [2007]; Durack Bown et al [2003]; Kivits [2009]; and Fox, Ward and O’Rourke [2005]) have reported. Citing his own studies, Rapley emphasises that the clinical consultation is seldom a one-off encounter; his participants meet and speak with several different clinicians, often in several different places and at different times, and also meet some of these more than once. Thus the clinical interaction is itself distributed, as well as contributing to a decision process that is further distributed across other, non-clinical encounters.

For the story told in this thesis, Rapley’s paper is an important part of the backdrop, but it takes a different direction in two important respects. First, the clinical challenge of facilitating shared decision making remains central in Rapley’s account; he specifies that he aims to facilitate research about ‘the decision making process in doctor-patient encounters’, implying that the other encounters he describes are relevant only insofar as they contribute to this process. In contrast, this thesis frames the decision making process that takes place outside clinical encounters as an object of interest in its own

right, and proposes that, regarding what people actually do, it may be at least as relevant as the process of making decisions with a doctor.

The second point at which my line of enquiry diverges from Rapley's concerns the nature of the process through which people make up their minds what to do. Although he begins by explicitly contrasting distributed decision making with the cognitive process central to most accounts of shared decision making and risk communication, Rapley does not offer any further exploration of this contrast between cognitive and other unspecified processes. The decisions he describes are presented as involving clearly delineated choices, even where they are reached over a period of time in which there have been several different encounters. Others such as Öhlén et al [2006], who foreshadow Rapley's emphasis on relational autonomy, also tacitly imply that the process of making a medication decision can be seen as choosing between options. Choosing is not necessarily a cognitive process, let alone a rational one; so there is no contradiction within Rapley's account, which offers a very helpful emphasis on temporal, spatial and interactional distribution. However, a model centred on choosing, whoever it involves and wherever and whenever it takes place, seems unlikely to inform a satisfactory story about the way people come to take longterm medication, or end up not taking it despite leaving their clinical encounter having 'decided' to do so.

Rather than trying to explain what people do in terms of what they choose to do, and how, the alternative approach adopted here frames taking regular medication as an inherently multiple practice which articulates very closely with other everyday practices. Some of these everyday practices are directly related to the medication, such as setting up and following a routine that reminds the person to take the pills, or arranging a convenient way to get a new supply before they run out; others, like the practices involved in constructing knowledge, and the performance of a presentable identity as someone who takes pills, contribute indirectly but nonetheless indispensably. So, alongside the literature on decision making, the backdrop to this thesis includes papers (like Dew et al [2014]) that present research about household practices, and those (such as Vassilev et al [2011]) that examine the way 'self-management' of chronic illness is actually a team effort in which small mundane contributions may be more crucial than the obvious medical input. In the end, having set out to study the way people take decisions about statins, it turns out that framing what is going on as 'taking decisions' constrains and distorts the picture. Deciding does come into it, especially the

distributed variety that Rapley describes as ‘decisions-in-action’, but the findings presented in Chapters 3-6 turn out to be inadequately explained by a story centred on the predominantly cognitive process of ‘making up one’s mind’. In the next chapter I describe some of the methodological decisions which led me to construct a practice-based account that offers a better fit with my findings, and which thus helped me achieve the objective I set out with: a plausible story to explain what goes on between someone leaving a clinical consultation with advice to take a statin and then either throwing her prescription straight in the bin or carrying on taking the pills regularly for years.

## Chapter 2: Methodology

### Introduction: methodological choices

In his methodological essay Philip Strong [2006/1979] suggests that, since certainty is very seldom attainable in social science research, ‘the best we can hope for... is a plausible story’ [p183]. The aim of this thesis is to produce a plausible story about the way people who have been offered statins come to end up either taking or not taking them. As Chapter 1 explains, this is a story about two groups of ideas: ideas about prevention, and ideas about decision making; I am particularly interested in the way deciding gets done outside the medical consulting room, in the everyday settings in which regular preventive medication is taken. The research presented here began with the question ‘How do people decide about statins?’; in this chapter I discuss the ontological and epistemological considerations that informed the way this question was refined and the methods I used to answer it.

The methodological decisions described here evolved incrementally over the course of the research project, but were constrained by two choices made at the start: to focus on statins, and to use interviews to generate data about how people decide about them. Statins were chosen as a particularly ‘pure’ example of a preventive medication, since, from a biomedical perspective, their only intended effect is to reduce cardiovascular risk. New knowledge concerning statins is likely to shed some light on the way people take or decline to take other preventive medications, and perhaps also a wider range of long-term medications; such new knowledge should also contribute to the growing literature about the conceptualisations of prevention and risk used by people whose doctor has identified them as being ‘at increased risk’ of future illness. Thus the project constitutes a case study, a framing that only became apparent to me in the course of pursuing it.

The decision to use interviews to generate data about how people decide about statins was based initially on two naïve assumptions: that decision-making would necessarily be a central character in a plausible story about how people come either to take or not to take statins; and that it might be possible to use interview data as the basis from which to build some inferences about what people think and feel, and thus to produce a credible account of their ‘lived experience’ which might in turn shed light on the way

they made up their minds about preventive medicine. At the start of this chapter I give a brief account of the flaws that became apparent in each of these early assumptions during the research process. Identifying these flaws contributed to a shift of focus: whereas the original research question was about the way people make up their minds about statins, implicitly a purely cognitive process, this question was later subsumed into a broader exploration of the web of everyday social practices through which regular pill-taking is carried on.

My aim in this chapter is to meet the recommendation Kelly [2010] makes in concluding her account of the role of theory in qualitative health research, by providing a transparent and theoretically informed account of the methodological choices made in the course of my research. Strong helpfully emphasises the importance of rigour in qualitative research both in relation to the methods used to maximise “the validity of what we know about... the world” (part of a quotation from the work of Ernest Gellner, p129 in Strong [2006/1979]) and in relation to the description of these methods. Heeding this emphasis, I have tried to problematise as many methodological assumptions as I can identify, and, later in the chapter, to present a precise and detailed account of my methods, in order to ‘reveal not what one knows but how one knows it’.

After explaining how I came to adopt a practice based framing for my research, I shall outline some of the ways people define social practices, and then describe how I set about studying them. I used many elements of the approach Strong expounds, for instance the framing of interview data as a context-specific performance, and the use of contradictions and discontinuities to afford a glimpse of the tacit norms that make sense of that performance. Several of these elements are foregrounded within a paper about joint interviewing, which is included later in this chapter before it concludes with a description of my research methods.

### **Decisions and risk as key objects of study – or not?**

At the beginning of this project, the research question was ‘How do people decide about statins?’ This question was framed by my perspective as a GP who had spent years attempting to involve patients in evidence based shared decisions about their medical care. To answer it, the topic guide used in the first few interviews included the words ‘decide’ or ‘decision’ six times. In the course of carrying out these interviews and

analysing the data they generated, it quickly became obvious that these questions were not very fruitful – they tended to elicit answers that were either very brief or told a story from which ‘deciding’ was virtually elided. Although people talked at length in response to more open questions about how they came either to take or not to take statins, there was very little indication of the weighing up of pros and cons central to the kind of decision making process I seek to facilitate within my consultations as a GP.

As well as ‘deciding’, the other topic I initially expected people to talk about in connection with statins was risk; to a doctor, ‘preventive’ longterm medication means ‘risk reducing’ medication. Analysing the data from early interviews, the paucity of talk about either ‘deciding’ or ‘risk’ seemed a striking negative finding. However, as I began to adopt a broader range of perspectives through working within a community of qualitative researchers, this negative framing appeared as an unhelpful analytic dead end, except insofar as it shed light on some potential consequences of the differences between a biomedical and a non-biomedical viewpoint. The way these differences persist alongside the increasingly porous boundary between medical and non-medical knowledge (Nettleton 2004) is discussed later in the thesis, particularly in Chapter 7.

Instead of constructing a story about what people do not do, the analytic approach described here aims to account for what they do do. This approach is illustrated in the Findings chapters of the thesis, and the sequence of these chapters indicates a progression through different stages of the analysis: Chapters 3 and 4 problematise the assumptions about risk, prevention and decision making that I began with; Chapter 5 takes a tangential look at what is going on, focused not on deciding but on the work people do to enact a presentable identity in the context of talk about pill-taking; and finally in Chapter 6 I return to examine and reconceptualise ‘deciding’, casting it as a social practice that is enacted within a web of practices through which people take care of themselves.

### **Attempting to study perceptions or beliefs**

Back in the early stages of the project, preparatory reading and discussion suggested the possibility that an interpretative approach might be useful in producing the plausible story I wanted, with particular strengths as a way of producing a rich, detailed description of participants’ perceptions of statins and their beliefs about prevention.

This idea was rejected early in the research process, as I came to consider the ontological and epistemological obstacles to studying what goes on inside people's heads.

### *Ontological issues*

Doubts about the stability of perceptions and beliefs as objects of study were prompted by moving beyond early descriptive data coding to more theoretically informed analysis; trying out different approaches, potential problems with this interpretative ontological stance became apparent, particularly through analysing data from joint interviews. As the paper later in this chapter explains, joint interviews generated valuable observational data about some of the ways in which couples worked together to co-produce an account, and data where the two participants contradicted or corrected one another was especially useful. Observing these couples negotiate multiple tensions to enact a shared presentation, and comparing this data with data from individual interviews, problematised a tendency when analysing individual interview data to reify beliefs and perceptions and consider them as stable, context-neutral entities.

In an article critiquing this tendency to reification, Radley and Billig [1996] argue that beliefs should not be assumed to be things 'held over the long term' that 'people ... merely have, as they might have eggs... in a basket'; instead the authors suggest that researchers should re-frame their object of study as a context-specific account which is shaped by the identity work it does for the speaker. This point is echoed by Murdoch et al [2013] in their account of the role of moral discourses in talk about medicine-taking. They are critical of much existing research that uses interviews to study views, attitudes, and experiences of illness: 'Talk within interviews is typically viewed as an accurate articulation of individual attitudes, isolated from the context of production, and similarly functioning to uphold the existence of the fixed individual attitude. By presupposing that individuals have fixed attitudes, the tools and data produced solipsistically substantiate the existence of such attitudes'. The last point, about finding what you set out to look for, is an element within Judith Green's [2009] warning that setting out to do research with a risk framing may well 'pre-empt the questions we ask and the answers generated'. The research presented here set out with a similarly prescriptive framing, asking a question about 'deciding' that directed enquiry towards a purely cognitive process; only through several iterative cycles of data generation and

analysis did the limitations of this framing become apparent, leading me to broaden the focus of enquiry by exploring the ways in which people come to take (or not to take) statins. The same limitation is visible within the literature on shared decision making; even an author like Rapley [2008], who sets out to make a significant move away from the prevalent framing of explorations of decision making as a one-off event involving a simple doctor-patient dyad, nonetheless constrains his own account by leaving ‘the decision’ centre stage, albeit presented as the end product of multiple interactions.

The practice of reifying perceptions, attitudes, values or experiences as stable objects of study is very prevalent in research about decision making, constituting a flaw that is particularly salient in the extensive literature about decision aids and thus a design flaw in the aids themselves. These decision aids are rational choice algorithms designed to be used by or with an individual patient in order to determine the best decision for that individual; the assumption is that the patient is the owner of a collection of perceptions which the decision aid might change by providing new information, and a collection of values which the aid incorporates into its calculations. Even where authors such as Charles et al [2005] identify and discuss a range of conceptual problems inherent in the decision aid project, including the artificiality of ‘values clarification exercises’, the objection is that such exercises are unlikely to be an effective tool to ‘reveal [the patient’s] true preferences’ or help her make a decision consistent with her ‘true values’. A more fundamental objection, however, seems to be Radley and Billig’s argument that to reify a stable set of values or preferences is to build a fatal oversimplification into the account, weakening its validity.

A different drawback of studying ‘lay perceptions’ and ‘beliefs’ is that this framing supports a tacit hierarchy of reliability which places perceptions and beliefs below medical ‘knowledge’. The implication is that, where doctors’ and patients’ knowledge differ, doctors are right; their knowledge is presented as ‘objective’, ‘factual’ and hence context neutral whereas patients’ is individual, contingent and ‘subjective’. In an account of a consultation about cholesterol, Gwyn et al [2003] make this point, having noted that the doctor keeps saying ‘I think...’ but ‘you feel...’: ‘It is interesting that whereas the patient is ascribed “feelings” on the subject ..... the doctor himself “thinks”’. “Thinking” is a rational, empirical exercise, whereas “feeling” is emphatically not’. In a review of papers about ‘patients’ views of medicines’, Pound et al [2005] challenge the



low status accorded to what patients say, noting that ‘worries [about side effects] have tended to be marginalised, or... treated as “beliefs about medicines”, despite the well documented existence of [side effects]’. In this statement, and in the way the authors develop it into a call for more research into medication side effects and better, ‘safer’ medicines, they seem to imply a positivist ontology that underpins the very distinction they are criticising: ‘beliefs’ are placed on one side of this dividing line, while facts whose implicitly real ‘existence’ is ‘well documented’ are placed on the other side. This dichotomy between beliefs and facts is particularly tricky to defend in the case of side effects because they often have no manifestations that can be confirmed objectively. In the paper in Chapter 6, I use reports of side effects as an example of the way my study participants use information in accounting for their medication decisions, and emphasise that talk about side effects is shaped by the story to which it contributes: people who are taking statins play down some unpleasant-sounding side effects, whereas people who are not taking statins use their similar-sounding experiences to explain their decision to stop taking the medication. Thus this example illustrates the limitations of any story that situates talk about side effects on one side or the other of a clear dividing line, casting such talk either as evidence about the ‘existence’ of side effects or as a straightforward reflection of what the speaker knows, believes or perceives.

Rather than focusing on the need to find useful new medications with fewer side effects, Pound et al’s [2005] statement about the marginalisation of patients’ knowledge could more profitably be developed into a discussion problematising widespread assumptions about different kinds of knowledge and the discourses that inform the way they are assessed and ranked within different communities of practice, as I attempt to do in Chapter 7. Pound et al point out that the social science community could be said to have reinforced the distinction between (and ranking of) biomedical and ‘lay’ knowledge about medicines, by tending ‘to focus on “perceptions” of medicines or the “meanings” people attach to medicines... [while neglecting] the physical reality of medicines and the effects they have’. This criticism is the starting point of calls by authors such as Timmermans and Haas [2008] for a new ‘sociology of disease’ that would move on from an exclusive focus on illness to engage with ‘the biology of disease’ and address questions about ‘whether a disease is ‘real’ or not’. This focus on ‘physical reality’ seems likely to perpetuate or even reinforce the hierarchical distinction between different kinds of knowledge; instead, the distinction itself may more usefully be cast as

an object of study. Studying this epistemological issue, alongside the ontological one highlighted by discussions of ‘reality’, seems particularly pertinent to endeavours to generate new knowledge that might be useful to health practitioners and policy makers, and thus to contribute to ‘sociology for health’.

### *Epistemological issues*

Even if the ontological objections to attempting to study perceptions or beliefs were to be overcome by cautious reflexivity, there is also an insurmountable epistemological objection: a leap of faith required to build inferences about what people think or feel from what they say. This is a problem about credibly demonstrating validity; its importance depends on the primary aim of the research, and also on the community within which it is presented – credibility is in the eye of the believer. If a thick, rich description of what is going on is cast as an end in itself, then peopling this description with beliefs and feelings may be said to produce a satisfactory story; within the medical community such a story, inferring what people believe or feel from what they say, is widely accepted as valid. A paper by Benson and Britten [2002], for example, reporting research that set out to ‘explore patients’ perceptions about anti-hypertensives’, illustrates this widespread tacit assumption that interview data is a robust basis for inferences about whether ‘patients held perceptions...’, ‘had reservations’ or ‘felt that taking drugs was “just not for them”’. The assumption is compounded by the implicit contention that establishing that ‘[most] interviewees... agreed ... that [the research report] encompassed their views’ helpfully increased the validity of the researchers’ inferences. This contention rests on assumptions both about the stability of ‘views’ and, more worryingly, about the relationship between views and what people say; Bourdieu describes the latter assumption, that one can deduce what people mean from what they say, as ‘the illusion of immediate understanding’ [1990, p26].

These assumptions are incompatible with the framing of an interview as a situated performance whose construction and presentation is shaped by a collection of morally infused objectives: the interviewee seeks to portray herself as sensible, responsible, rational, helpful to the interviewer and so forth. The strength and coherence of this framing is cogently described by Strong [2006/1979], who draws on Goffman’s writings to support and explain an analytic approach that casts interview data as a source of clues to the ‘rules’ being followed. This approach involves a redefinition of ‘interview data’, broadening it to include observational data alongside what is said, and

also drawing attention particularly to what is left unsaid – in Strong’s words, to ‘what might have been there but was instead systematically excluded’ [p4]. Framing interview data in this way drew my attention to inescapable epistemological concerns about the validity of knowledge about other people’s perceptions and views. Added to ontological concerns about the stability of these objects, these led me to discard the idea of attempting to study people’s perceptions of statins. Instead I set out to use interview data in two different ways. First, the data constitute a source of clues about the discursive frameworks that make sense of what is said. Second, they provide observational data concerning performative practices such as knowledge construction, although this second usage has potential pitfalls which are discussed in the paper that follows. As well as treating discursive frameworks as worthy of study in their own right, they can also be cast as one of the constituents of the social practices which are the key objects of study in the account I construct in this thesis.

### **Studying social practices: what and how**

Having identified a poor fit between my data and the decision-centred story I had initially set out to construct, and having come to recognise the obstacles to attempting to study people’s beliefs about risk or prevention, I made a fresh analytic start informed by the overall aim of the study, which was to deepen understanding of a particular type of public health intervention: getting eligible people to take longterm preventive medication. From this viewpoint an alternative approach seemed obvious: the central objective must be to produce a plausible story about how people who have been offered statins come either to take or not to take them. To align with the aim of informing attempts to influence what people do, the central character in this story must be the practice of taking regular medication; decision-making and risk may well turn out to play only supporting roles. Alongside this top-down reason to adopt a practice based framing, there was also an empirically grounded one: whereas talk about deciding and risk were largely absent from the data, multiple interactions with a variety of people and material objects were very frequently referenced and sometimes directly observed. Thus the aim of the study and the research already done both directed my attention to the extensive literature concerning social practices.

### ***What are social practices?***

Beyond Schatzki's [2001] deliberately general definition of practices as 'arrays of activity', the word is used to represent different concepts by different authors. These ontological differences concern the way discursive elements are handled: at one end of the spectrum, practices are presented as activities, while at the other end practices incorporate both activities and the discourses that make them intelligible. Timmermans and Haas [2008], authors of a call to delineate a sociology of disease (distinct from the sociology of illness), situate themselves at the narrow end of this spectrum, stating that 'an analysis of practice concerns who does what, when, where, and with what consequences'. This statement implies that practices are equated with activities; the articulations through which activities combine to form Shatzki's 'arrays' are elided from Timmermans and Haas' account, as are the discursive frameworks that produce and make sense of activity.

Discourses and their relation to activities are brought back into the picture in Barnes' [2001, p19] definition of practices as 'socially recognised forms of activity, done on the basis of what members learn from others'. Barnes goes on [p22] to emphasise that to understand 'social life' it is necessary to consider not only practices but also the discourses (in Barnes' terms, the 'aims, experience and knowledge') 'that lead people to enact them'. Thus practices and discourses are presented as separate objects in this account. Rouse [2001] goes further, situating discourses as a central element of social practices; his account contrasts two alternative uses of the term 'practices', one conceiving them, as Barnes does, simply as regular patterns of activity, while the other, Rouse's preferred use, incorporates a normative dimension. Rouse's 'normative conception of practices' [p189] seems to accord with Foucault's (1991b, p75) understanding of practices as constituted both by activities and by the discourses that shape them: 'places where what is said and what is done, rules imposed and reasons given, the planned and the taken for granted meet and interconnect'. Giddens [1991, p36] highlights one of these interconnections, between actions and taken-for-granted knowledge: 'Many of the elements of being able to "go on" are carried out at the level of practical consciousness, incorporated within the continuity of everyday actions'. This is an interconnection of particular interest in the context of daily pill taking, drawing attention to the way it is enacted within a web of everyday routines which are informed at least partly by tacit practical knowledge, an idea I return to in Chapter 6.

In Bourdieu's [1990] account, tacit practical knowledge is credited with informing practices while theoretical, explicit knowledge makes only a peripheral contribution: theoretical knowledge can inform change in practices only if the habitus engenders 'conditions of possibility for change' [p26], making a possible new practice 'thinkable' [Nettleton and Green 2014]. This insight points to parallels between an ontology of practices and one centred on discourses, 'set[s] of rules which ...define the limits and forms of...the sayable' [Foucault 1991a, pp59 -60]; a broad definition of 'practices' that presents them as comprising not only activities but discourses is key to the analysis presented here. This definition, and its roots in Bourdieu's theory of practice, are helpfully discussed in Nettleton and Green's account: drawing on data from an interview-based study looking at physical activity, they explore a world of social practices where what people do is shaped by both 'social and mental structures' which can be seen as 'mutually constituting'. Using case studies to illustrate that even material practices are shaped by discursive frameworks, and so cannot be understood simply as things people do, Nettleton and Green highlight the strengths of a social practice approach for understanding the challenges that limit the success of many public health interventions. Thus although many such interventions measure their success in terms of their effect on what people do – material practices – just studying these material practices in isolation is unlikely to be helpful; for example, to understand how people come either to take or not to take statins after being advised to do so, it is necessary to recognise that pill taking is inextricably entangled within a web of social practices that includes both material and discursive elements. This web is my object of study here.

My aim, to explore how people decide what to do, echoes the way 'what to do?' is foregrounded in Annemarie Mol's [2002] account of her ethnographic study of the ways people decide what to do for a patient with atherosclerosis. But my focus on the practices themselves is different from the ontological approach she advocates: Mol's object of study is not the practices themselves but the objects these practices enact, objects she conceptualises as inherently multiple. For example, having described the various practices through which a patient and a hospital team assess the patient's problem, she casts the various results of these assessment processes as a collection of 'objects in practice' that are all called atherosclerosis [pp149-150], both severally and collectively. This difference in ontological assumptions is inseparable from a difference between Mol's epistemological assumptions and mine. Whereas I frame interview data

as the product of a situated, context-specific performance, Mol explicitly distances herself from the concept of performance, which she says suggests a spurious distinction between what is made visible and a 'backstage' reality. She recasts reality as the product of enactment: 'If an object is real this is because it is part of a practice. It is a reality *enacted*' [p44]. This stance enables her to argue that 'what people say in an interview doesn't only reveal their perspective, but also tells about events they have lived through' [p15], and that by adopting this framing when listening to an interviewee, 'an illness takes shape that is both material and active' [p20]. In a different encounter, with a different listener, a different event or illness may be enacted; to Mol, these multiple entities together constitute the 'real' event or illness. Thus choosing a definition of practices shapes the way one sets out to study them: having framed interviews themselves as social practices whose discursive elements will shape 'what people say', it follows that I use my interview data primarily as a source of clues about these discursive elements.

### ***How to study practices***

Like studying perceptions and beliefs, studying practices requires concerns to be addressed about two related issues: the stability of the object of study, and the ways it is possible to study it. That these two concerns are closely linked is underlined by Bourdieu's [1990] injunction to researchers who study practices, that they must acknowledge not only 'the particular viewpoint that a "situated and dated" observer takes up vis à vis the object', but also the 'much more fundamental alteration...that is performed on practice by ....constituting it as an object (of observation and analysis)' [p27]. Bourdieu's 'fundamental alteration' here is a conceptual one; his warning is given within an attack on objectivist epistemological approaches that imply the possibility of 'an absolute viewpoint' [p28]. Instead he recommends that 'all would-be scientific discourse on the social world [should be] prefaced by a sign meaning "everything takes place as if..."', which....would constantly recall the epistemological status of such discourse' [p29]. This recommendation is echoed by Strong's advice that researchers should adopt the relatively modest aim of producing 'a plausible story' about what is going on, strengthening plausibility by giving a detailed account of the methods by which the story was built.

In the context of using interviews to study practices, a different, more pragmatic alteration also needs to be acknowledged: interview data are inevitably shaped by the

context in which they are generated, as participants try to help the interviewer by offering coherent, rational accounts of what they do. The interview is itself a social practice, incorporating discourses that are sometimes surfaced by what is either said or visibly left unsaid. So interview data can be used as a source of clues about the discourses that inform what is said. The paper below explores the particular advantages of dyadic couple interviews as a source of such clues, and also discusses the need for careful reflexivity concerning claims of ‘naturalness’ in relation to observational data about the practice of presenting an account in an interview. These claims are made particularly often about couple and other group interviews, where the way participants interact to co-construct a shared account may constitute an object of study in itself. As well as these shared performative practices and the discursive framings that inform them, a third object of study is considered in the paper: material practices. It is in relation to studying material practices that there is a particularly clear divide between Bourdieu’s stance and the objectivism implicit, for example, in Timmermans and Haas’ recommendation to study ‘who does what, when, where’ in relation to diseases.

In a paper defending the validity of interviewing as a method of studying material practices, Hitchings [2012], too, implicitly conceptualises practices as activities; the norms which shape them are cast as separate from the activities themselves. Using this conception of practices, Hitchings draws on data from interviews about physical activity to suggest that it is possible to base credible inferences about what people do from what they say they do when asked in interviews. Hitchings’ focus on routine practices is similar to mine, and his claim that ‘people can often talk in quite revealing ways about actions they may usually take as a matter of course’ is one I echo in this thesis. We disagree, however, about what it is that talk can reveal and about the analytic moves needed to reveal it; Hitchings appears to succumb to the temptation Nettleton and Green [2014] describe as ‘the seductive reading’ of interviewees’ cited reasons for adopting or not adopting certain practices, a reading that assumes that practices are shaped by the theoretical knowledge such reasons reference. In the context of medication practices, this assumption is the basis for much research and debate about ‘barriers to adherence’ [McHorney and Spain 2010], for example, leading to the hope that adherence to longterm medication can be increased by dealing with these reasons or barriers. Hitchings explicitly foregrounds theoretical knowledge, noting for instance that he obtained a particularly comprehensive and detailed list of ‘the factors sustaining their

routines' from interviewees whom he casts as 'educated individuals [who] liked the intellectual challenge of working through [these] factors'.

Nettleton and Green [2014], too, draw on interview data about physical activity, but alongside what is said, they highlight other constituents of interview data in their account. They provide the example of an interview where a group of interviewees laughed uproariously when asked whether they rode bicycles, before politely offering a list of rational reasons for not cycling. Nettleton and Green use this laughter in their analysis; rather than simply framing their interview data as a recital of true facts about participants' concerns, or as reasons for choices, they suggest that what is said may represent post hoc rationalisations constructed for the interview. In their account, interviewees talked about factors that would make cycling impossible for them, thus presenting sensible explanations for their actions, but these actions were also informed by tacit discourses and practical knowledge that made cycling a laughably unthinkable idea. This illustrates a methodological challenge, and also a way to overcome it; the challenge is to use what is said and done in interviews as the basis for credible inferences about things that 'go without saying'. In the paper that follows, we discuss some of the ways in which interviews can generate data that help to build these inferences and meet that challenge, and how observational data can be combined with interviewees' talk about everyday practices to shed a credible light both on material routines and on the discursive framings that shape them. Discussing some of the potential advantages and pitfalls of using this kind of data, we focus particularly on the additional analytic purchase offered by interviewing couples together rather than separately.



## **Paper 1: Using Joint Interviews to add Analytic Value**

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## **Abstract**

Joint interviewing has been frequently used in health research, and is the subject of a growing methodological literature. We review this literature, and build on it by drawing on a case study of how people make decisions about taking statins. This highlights two ways in which a dyadic approach to joint interviewing can add analytic value compared to individual interviewing. First, the analysis of interaction within joint interviews can help to explicate tacit knowledge, and to illuminate the range of often hard-to-access resources that are drawn upon in making decisions. Second, joint interviews mitigate some of the weaknesses of interviewing as a method for studying practices; we offer a cautious defence of the often-tacit assumption that the “naturalness” of joint interviews strengthens their credibility as the basis for analytic inferences. We suggest that joint interviews are a particularly appropriate method for studying complex shared practices such as making health decisions.

## **Key words**

qualitative analysis; interviews; decision making; storytelling; joint interviews

As both Morris [2001] and Morgan et al [2013] have noted, joint interviews have a long history and have been extensively used in health research, yet they remain under-explored methodologically, and largely ignored in textbook coverage of interviewing. However, a small but growing literature, predominantly from studies of chronic illness and disability, does address the practical, ethical and methodological implications of interviewing two people together. We aim to build on this literature by suggesting that joint interviews provide some analytical advantages over individual interviews in studying tacit knowledge and health practices.

We first map the different ways in which joint interviews have been defined and used in health research, noting that a primary advantage claimed has often been for research questions which address interaction between the participants interviewed. Joint interviews have been used less often in studies of health practices, in part reflecting methodological reservations about how far interviews in general are a useful source of data on what people do. We then use examples from research conducted by Louisa Polak to suggest two ways in which joint interviews provide some analytical purchase that offsets the methodological limitations of using interview data. The data are drawn from a study of how people make decisions about taking statins, in which many interviewees preferred to be interviewed with their partner. First, we found these joint interviews to be a particularly fruitful source of clues to the ways in which decisions were made, offering “added value” compared to individual interview data. Second, in terms of providing data on practices, although we problematise the widespread tendency to treat data from joint interviews as more “natural” than one-to-one interviews, we do suggest that if handled with care and reflexivity such data can be used as a credible basis for claims about practices, thus providing a further analytic advantage of joint interviewing compared with individual interviews.

## **Background: literature on joint interviewing**

### ***Defining joint and dyadic interviews***

Joint interviews involve an encounter between an interviewer and a dyad: two interviewees. In research reports, interviews with two participants have variously been called joint interviews, couple interviews, conjoint interviews, and dyadic interviews. However, these terms are used in rather different ways across the literature, in part

depending on whether the focus is on data collection or analysis. Morgan et al [2013], for instance, discuss dyadic interviews as any which bring together two participants in the same interview, drawing on examples from interviews with two people who do not necessarily have a prior relationship. Such interviews, they suggest, combine some of the advantages of the focus group interview (such as the opportunity for participants to support and prompt each other) whilst reducing some of the drawbacks, such as the limited access offered by larger groups to detailed narratives from each participant. Morris [2001], too, positions joint interviews between individual interviews and focus groups, although she emphasizes the analytic possibilities that result from the two interviewees' prior relationship, implying that she sees joint interviews as a subset specifically of natural group interviews.

Caldwell [2014] helpfully defines a dyadic approach as “a qualitative approach that ... embraces [the existence of] an interdependent relationship between individuals ... as a source of information rather than attempting to control for it”. Here, “dyadic” refers to an orientation to the research in general, and specifically the data analysis, rather than data collection methods. This orientation applies as well to groups larger than two, highlighting the fact that dyadic approaches have much in common with research addressing multiple perspectives within larger groups such as families or households. Several authors consider the analytic implications of these larger-group approaches; for instance, Kitzinger [1994] highlights the strength of interviewing natural groups as a means to illuminate tacit knowledge; and Duggleby [2005] describes various different approaches to analysing group interaction data from focus groups. Dyadic interviewing has also been used to refer to methods where data from separate interviews with each of a couple are analysed as a single unit. Eisikovits and Koren [2010], for example, include such interviews in their review of dyadic interviewing, as well as situations where the two participants are interviewed together, and indeed make a strong case for taking a dyadic approach to separately collected narratives. This has similarities to multiperspective approaches used with a larger set of individual interviews, and for instance McCarthy et al [2003] discuss the advantages and disadvantages of such approaches for studying family lives.

These overlapping definitions, and lack of consensus around methodological terms, result in occasional difficulty in ascertaining which kind of interviewing or

analysis was actually used in an empirical study. Here, we refer to “joint interviews” to mean interviews with two people who have a prior relationship, interviewed at the same time, and a “dyadic approach” as one which involves analysis that utilises the interaction between the participants. This interaction, as Allan [1980] says, may “provide insight of a form hard to obtain from individual interviews”.

### ***Interaction as an advantage or a problem***

Most of the advantages and disadvantages of joint interviewing stem from the interaction between the two participants; as Eisikovits and Koren [2010] point out, access to this interaction is a central feature of joint interviewing. The advantages, as described by Allan [1980], derive from two kinds of opportunity afforded by interaction between interviewees: first, the opportunity to study the interaction itself; and second, the opportunity to obtain data which is generated by that interaction. Many authors have followed in Allan’s footsteps, presenting accounts of these advantages of joint interviewing in relation to a variety of methodologies and research objectives. For instance, in studying gender relations, Valentine [1999] gives a detailed account of the benefits of joint interviewing, both in illuminating the process of negotiating a shared account, and in generating a richer and more detailed account because participants prompt one another; Torgé [2013] suggests that in a study of “spousal care and support in a disability context”, joint interviews provided access to “we-talk”, in which the participants discursively co-produce themselves as a dyad working together to deal with shared problems; and Taylor and de Vocht [2011] describe using joint interviews within a phenomenological approach, to elucidate the couple’s shared perspectives and understandings about experiences of sexuality and intimacy.

Most of those who write about the strengths of joint interviewing also discuss its pitfalls: key to most of these is that interaction between the participants may have the effect of silencing an individual’s account. Particularly when talking about sensitive topics, things may well remain unsaid which might be said in an individual interview; for example, Eisikovits and Koren [2010] highlight the fact that, in their study of couplehood in old age, separate interviews within dyads elicited data which joint interviews would not have done, such as accounts of concern to protect one’s partner from worries. Several authors discuss the risk that one interviewee may dominate the

other (eg. Arksey [1996]; Morris [2001]), and highlight the ways in which narratives may be gendered. For instance, both Seale et al [2008] and Valentine [1999] found women often dominated discussion during joint interviews with their male partners, particularly on topics such as pregnancy or child-rearing.

Prompting talk about intimate topics within a joint interview raises ethical concerns about possible inadvertent disclosure of individuals' private accounts, and the possibility of harm from even unprompted disclosures needs consideration when seeking consent for joint interviews. Offering a choice between individual or joint interviews does not fully address this ethical concern, as Mellor et al [2013] point out. Taylor and de Vocht [2011], for instance, describe the hope that such a choice would enable "individuals who valued the freedom to express things they would not want their partner to know [to] choose an option that would provide for this", but they later undermine this reassuring idea, echoing Morris's [2001] point that people may be reluctant to imply that they have secrets from their partner, and prefer to present themselves to the interviewer as what Radcliffe et al [2013] describe as "a normal, united couple". Thus, the fact that participants choose a joint interview is data in itself.

These constraints clearly shape the data generated in joint interviews, and consequently they inform choice of method given a particular research question and methodology. For example, to address questions concerning men's perspectives per se, individual interviews may be preferred, as Seale et al [2008] suggest. However, where the focus is on understanding "the contested realities of shared lives" [Valentine, 1999], then there may be significant advantages in using joint interviews, to provide observational data on how men's perspectives are undermined or moderated in negotiating family health practices. While not claiming that joint interviewing is better than individual interviewing, most authors implicitly agree with Arksey [1996] that it generates data which is qualitatively different. This difference has been exploited in a variety of contexts within health research.

***Living with chronic illness: a focus on the individual or on the couple?***

Clearly the methodological and practical advantages of joint interviews are more likely to come into play with some participants, topics and research questions than others. Studies of living with long-term illness have been a common setting for joint interviewing, perhaps in part because partners, informal carers and significant others

may “share the burden of the work of managing the illness” [Corbin and Strauss, 1985]. Joint interviewing, as in Torgé’s [2013] study of older couples living with chronic illness and disability, may be a deliberate research strategy, employed to map, document and acknowledge this “sharing”, and to redress the elision of informal care work from much health writing and policy. The fact that this work is shared has practical implications for data collection: researchers are at times faced by unplanned joint interviews, where individual interviewees are joined, uninvited, by carers or family members. For example Pickard and Rogers [2012] studied the way “family and familiars” support self-care and knowledge construction in people with chronic comorbidities; they mention an inadvertent joint interview, where the son joined a meeting between his mother and the interviewer, although they only report their data from this encounter in terms of what he said about his role.

Even where joint interviews are deliberately planned as the data collection strategy, this does not necessarily imply a dyadic approach to analysis of the data. Two different non-dyadic approaches are commonly used. In the first, the couple is treated as the unit of analysis, and described as if it was a single individual talking about, for instance, “their” feelings and about the effects of prostate cancer on “their” daily lives [Harden, Northouse and Mood, 2006]. A second, more widespread, approach treats data as coming from two separate individuals; for instance Öhlén et al [2006] explicitly disclaim an intention to treat “the patient and significant other data . . . in a dyadic manner” in their study of the involvement of significant others in what they describe as “the patient’s” decision-making. This second stance is widely implicit elsewhere, particularly where the two individuals may share experiences, but relate to those experiences differently: for example within the literature on couples affected by dementia [Hellstrom, Nolan and Lundh, 2005; Roach, Keady, Bee and Williams, 2014; Robinson, Clare and Evans, 2005]. Here, the aim of using joint interviews is to study two people rather than the couple; the focus of analysis is then not so much on interactions, but on the two perspectives elicited from the one interview.

There is, however, a smaller literature on living with illness that does utilise joint interviews analysed with a dyadic approach and discusses the analytic possibilities this approach may provide. Most of these possibilities arise from the opportunity of observing shared storytelling during joint interviews, a feature many authors

emphasize (see, for instance, Allan [1980]; Bjornholt and Farstad [2014]; Gerhardt [1991]; Radley [1989]; Roach et al [2013]; Sakellariou, Boniface and Brown [2013]; Torgé [2013]). Radley [1989] notes that such public story-telling is an important component of the often-shared biographical work involved in living with a chronic illness. This shared work has implications for what it is to be “ill” or disabled, or to live with an ill or disabled partner. Manzo et al [1995], for instance, use conversation analysis to look at how the partners of stroke patients co-created narratives in a joint interview about the stroke and its aftermath: in interrupting and correcting the story, spouses contributed, they argue, to the disempowering of the stroke patient. Radcliffe et al [2013], also in a study of stroke survivors and spouses, analyses interaction and describes the different ways in which couples co-present themselves. Gerhardt [1991] draws on a couple’s shared story (about the man’s heart operation) to study their shared social reality and the woman’s role within this. These examples illustrate that dyadic analysis is important for understanding how, and whose, stories get told about chronic illness, and for studying the effects of the major disruptions of such illness, not only on the ill person but also on their significant other, and on the relationship between them.

### ***Studying mundane health practices***

The majority of studies using joint interviews entail, then, interviews with couples in the context of chronic illness or disability - with a rationale that significant others are central to the experience and management of illness, and that the relationship between patient and carer is an important topic of research in its own right. However, a similar rationale also applies to many everyday health practices, such as the use of non-prescription remedies, or the decision to take preventative medications. Our knowledge of, attitudes to, and use of medications and health technologies are rooted in social interaction, and others (families, workmates, friends) inform and shape our practices. This has been a common reason for using natural groups in research, with Kitzinger [1994], for instance, writing on how natural groups provide an opportunity to observe in action some of the social processes which shape knowledge and values. Where people live with a partner, the dyad of the couple is likely to be a key site for such processes; yet joint interviews have rarely been reported as sources of similar data.



In studies of household practices, the focus of research has predominantly been orientated to individuals' roles or accounts, with authors tacitly implying that interviews were with individuals, rather than household groups. One exception is Dew and colleagues [2014], who used "household interviews" to look at the range of medication practices within households, asking participants "to produce all medications and discuss them as a household group". The authors suggest that some interviews at least were joint, mentioning couples who challenged each other's accounts. However, they do not specifically reflect on the use of joint interviews; most examples are quotes from single participants, and the interactive data is used simply to point to occasional disagreements and note that "households themselves are not . . . unified". Carter et al [2013], in a study of how electric toothbrushes become adopted or not in particular households, do specify that they interviewed both individuals and households as "natural groups", and comment on some advantages of each as regards both data collection and analytic possibilities. They highlight the potential of household interviews "to produce invaluable data on the ways in which actors ... technologies and ... environments interrelate", underlining the value of this method as a means of studying interactions and shared practices. There have been, though, few examples of using joint interviews for studying health practices. We therefore now turn to a study of the decision to take statins, to explore what analytical value joint interviews might have for studies that are not about interaction per se, and not related specifically to living with chronic illness.

### **Joint interviews in a study of how people decide about statins**

Our examples are from a study which aimed to answer the question "How do people make up their minds about preventative medication?" by looking at decisions about statins. Early on, it became apparent that a fundamental component of the answer was "In a distributed way" [Rapley, 2008], rather than simply "In a clinical consultation". This informed the decision to collect data in a non-clinical setting, chiefly by interviewing people in their own homes. It also suggested that interviewing people together with a significant other, when possible, might be useful.

### ***The study methods***

Interviewees were recruited in community settings including lunch clubs, recreational organisations and snowballing from initial participants living in one area of England, East Anglia. The only criteria for inclusion were that participants were aged over 50 and had been offered a statin. The choice of whether to be interviewed alone or with a partner was made by the interviewees; most of those who lived with a partner chose a joint interview. The final sample included 39 participants, with 13 couples (all married) and 13 individual interviews. In many couples, both partners had been offered statins, something which often only emerged during the interview. All the couples chose to be interviewed at home. Having first obtained consent from both partners, Louisa Polak conducted and recorded all interviews and had them transcribed, changing all names and identifying details.

Interviews were semi-structured, with a brief topic guide covering participants' state of health; where their knowledge about health came from; how they looked after their health; and their decisions about and use of medication. This brevity allowed Polak to pick up leads opportunistically, inviting interviewees to elaborate. We analysed the data using elements of a grounded theory approach [Strauss, 1987]: initial open coding was followed by an iterative process of comparison both with other data and with the literature to inform subsequent cycles of data collection and analysis. The analysis was inductive in that we did not start with a particular set of hypotheses, but rather with an open question about what was "going on" when individuals decided (or not) to take statins after an offer from a doctor. This article does not aim to report on the substantive findings of this analysis, but rather to focus on how the joint interviews in the dataset provided particular analytical strengths for exploring everyday decision-making.

These gains from the joint interviews were an unexpected finding. Analysis of interviews with couples facilitated insights which individual interviews would not have done, and, we argue, strengthened the credibility of inferences from the data in two key areas. These were, first, the ways in which shared storytelling and knowledge construction helped explicate the tacit resources drawn on to make decisions; and second, providing access to everyday, material practices such as pill-taking.

***Shared storytelling and the co-construction of knowledge.***

The joint interviews offered many examples of shared storytelling, providing strong evidence that constructing a coherent and presentable story can be a team effort rather than a solo project. Two kinds of work constitute this team effort: co-presentation of a shared performance; and co-construction of knowledge and its application to jointly-owned problems. These are practices which can be observed happening during joint interviews.

***Shared performances.***

The following excerpt shows the work of shared story telling being done: Vic and Janet collaborate in presenting themselves (to the interviewer and to themselves) as sensible, knowledgeable people, who still have the power to make choices despite the major biographical disruption produced by Vic's heart attack. They are talking about advice given after this event; in this and all the other excerpts in this article, the emphases are those given by the speakers.

Janet: I came with you and you made a choice of which one you wanted to go to and you felt that the gym was more beneficial to you, than, just going and listening about diet because, you know what you shouldn't eat, and what you should eat.

Interviewer: So you got no surprises when they said, you already felt you knew that did you?

Vic: Yes it was really, we were just interested to read, to see if we were right, if we could pick up anything new. We didn't have to be told.

The way in which the two take turns to reply, dovetailing their contributions and switching between personal pronouns, demonstrate that this story is a joint production: there is "we-talk" as well as "I" talk here, with the couple collaborating on the story of therapeutic choices made. Not all shared presentations are constructed in this harmonious way, and contradictions can be particularly illuminating. Here, the self-presentation work done by Don's account is highlighted by Mary as she contradicts him:

Don (D): We eat a lot of fish and things like that, so I wouldn't say that we had sort of, fatty sort of diets -

Mary (M): We have fish and chips once a week

D: Yeah, we do occasionally,

M: Once a week

D: Well, it's not always once a week

M: *[laughs]*

D: Um, but that's about all, that's right. And I did ask, what sort of fat it was all cooked in, and that sort of thing, so, no, fat doesn't really sort of feature on our, you know our normal sort of diet

M: Well – *[inaudible comment]* ...

D: Yes, and take-aways very, very seldom, I mean and –

M: *[laughs]*

The contradictions implicit in Mary's laughing during this exchange might relate to the relative expertise of the two participants on the couple's diet: they work to undermine Don as a reliable witness on food provision within their household, with her providing clarifications, and trumping his attempt to downplay the regularity of the fish and chip dinner. At one level, this interaction is merely a reminder of the danger of trying to infer what Don does eat from what he says he eats, with Mary claiming some privileged status as an informant on the couple's diet. Her qualifying comments and laughter also undermine Don's attempts to present himself as a person who is particularly "virtuous" in respect of dietary choices. Shared storytelling, then, provides not only insight into interaction itself and how the dyad collaborates on health talk, but can also provide some useful analytical purchase on the claims people make about what they do, which would not be possible using individual interviews.

*Negotiating, co-constructing and using knowledge.*

In these shared stories, there are also opportunities to observe the material practices of information-gathering. One challenge of exploring how people do make decisions about statins is that much of the less-tangible work of accessing, assessing and using information is invisible. "Making the decision" is a process which draws on resources including information from, for instance, newspaper articles, health professionals, or friends. These sources might be remembered and recalled in interviews, but other background information, part of the general stock of "what people know", is less easily

remembered. Both these explicit and more tacit sets of knowledge are put into play with a set of more or less malleable norms about health maintenance, such as professed reluctance to take pills. In an individual interview, accessing the diverse sources of information that might coalesce to be “what you know” about statins is challenging. However, in joint interviews, couples often reproduced this process within the interview, working through with the interviewer and each other the ways in which knowledge was gradually built up into a coherent, or at least useable, whole. This provides a privileged insight into the overlapping processes of gathering and assessing information. Here, for instance, Violet and Jim demonstrate in their shared account the ways in which they work together to assess one source of information (friends’ experiences), and how they handle contradictions.

Violet (V): Ann came off of them because they disagreed with her.

Jim (J): In what way?

V: I can’t remember now, there was so many different bits *[laughs]*

J: Only Bert down the allotment there, he’s on the same thing as me

V: I think they upset Ann

J: And over the road there is Chris, who I go down the gym with now, he was another builder he was in competition with me when we were in the business, and he was having a talk with my mate and you were talking to his wife outside weren’t you. Anyway I spoke to Chris and he’s on statins and he has got no bother with them.

It is possible that this list of others with comparable experiences would also have been rehearsed in an individual interview, but unlikely: there is considerable interactive work being done by the interviewees themselves here, in prompting each other and reminding each other of the various sources of experiential evidence they have accessed. In this exchange, one shared tacit assumption that is surfaced by their joint description is that comparisons with people similar to oneself are a useful source of information. The exchange also provides insights into how inconsistencies between different people’s reports are integrated, in how Jim is reassured on balance by the experiences of friends who had “no bother”. Joint interviews therefore provided opportunities to observe the process through which interviewees built such shared

bodies of usable knowledge from an assemblage of dispersed and sometimes conflicting information.

Some elements of these assemblages remain opaque in joint interviews. In our data set, participants referred to sources including named people, as in the last excerpt, and specific advice provided by health professionals, but also to generic sources of knowledge indicated by phrases such as “they say”, and to tacit assumptions about normative approaches to health care or health maintenance. The careful analysis of individual interviews may, of course, enable some inferences about the underlying assumptions that participants draw on; but joint interviews have the advantage of often making these more visible. An interesting comparison may be made between two excerpts from the same interview. The first suggests one tacit assumption of the interviewees: that doctors’ advice is to be heeded.

Ron (R): I’ve been to the doctor

Felicity: He says you can’t take Crampex

R: Can’t take Crampex or anything like that

This assumption could be inferred in the same way if Felicity had not spoken: the interaction here does not necessarily enable the work of surfacing tacit knowledge. What the joint interview may add, though, is some explicit reflection on these assumptions. In commenting on their partner’s decision making, participants at times overtly signalled assumptions made, or normative values. A second excerpt from the same couple highlights this work, in that Felicity comments directly on Ron’s views, thus providing a more nuanced picture of the role of tacit values such as “trusting what doctors say”:

Ron: They just told me that I had to take them [statins], that I had to take them for the rest of my life so I just accepted it.

Felicity: Ron does accept things like that. He thinks doctors are gods and if they say something he’ll do it.

That Felicity marks Ron’s willingness to trust doctors as an orientation of him, personally, rather than an implicit value, suggests that rather than being an

unquestioned assumption made by the couple, it was one that can be debated, and which might not inevitably be a determining factor.

Felicity's reflection on Ron's rationale in this exchange may be particularly explicit, but there were several other examples where discussion between the two interviewees adds analytic value in a similar way. For instance, the following exchange highlights a question which turns out to be central to the decision to take medications: What, for participants, constitutes "having a condition" and hence "needing" treatment? Here, Mary's "But if ..." prompts Don to elaborate on his initial statement, and in doing so to reflect on the meaning of "a condition", and its properties:

Don (D): I'd prefer not to take any tablets ... if you can keep yourself healthy, in terms of sort of some exercise, and a good sort of balanced diet, then why should you take tablets, for anything at all.

Mary (M): But if you have a condition you would

D: Well if you have a condition well that's right, and I think in your case, I mean we've had more than one sort of episode, haven't we, Mary, of where you needed medication. So that to me is a different -

M: Scenario

D: It's - it's a different sort of situation, to the one which I'm in, which is just ... maintaining, sort of a, a healthy body.

Thus the interactive work of the participants themselves aids the explication of the factors which influence decisions: in this case, common-sense understandings of what kinds of situations legitimate medication use. These are factors that may have remained tacit without the couple unpacking their own assumptions in the story.

Even when such values remain tacit, in that they are not explicated overtly in participants' utterances, a joint interview can provide insights into ways in which these elements are integrated into decision making. In the following excerpt, Claire and Walter refer to a range of information sources which are in tension when deciding whether to call an ambulance. As well as shedding light on these sources, the excerpt also demonstrates how joint interviewing allows observation of the way Claire and Walter collaborate to construct usable knowledge, and how they bring that knowledge into play to make, as well as account for, decisions. Claire's "we called" suggests that

such decisions are shared, based on a negotiated shared body of knowledge about health and health behaviours. This short interchange also draws on three particular elements in accounting for their decision. The first is flagged explicitly: the direct advice on what Claire has been told to do if she needs to use her puffer twice. The second and third, however, remain implicit in this exchange: they are the value placed upon not making a fuss, and the value placed upon being sensibly cautious about one's health.

Claire: . . . we called the ambulance out twice and it goes against my grain that I don't want to be you know like Peter and the Wolf.

Walter: But you don't get a choice if you are in pain you cannot question that, because you don't get a second chance.

Claire: Well, it is that little puffer - if you take it twice you need to call, and I am embarrassed to ring up, you know, I just think that I am not ill enough.

Here, the interaction itself provides a chance for the two participants to rehearse the conflicting and difficult-to-manage obligations on patients to seek emergency care appropriately, neither too readily nor too late. Again, these tensions might have been revealed in an individual interview, but the dialogue form, unlike an individual interview, enables the two contrasting values (not being "Peter and the Wolf" versus "needing to call") to be explicated by the couple without risking an incoherent narrative. The exchange also allows the two participants to demonstrate, through the story, how the tensions were resolved in this particular decision.

In summary, performative practices such as storytelling in joint interviews can shed light on more than the interaction itself. They provide some insights into how useable bodies of knowledge are assembled by the couple, and how this knowledge is utilised in practice in making health care decisions. Although such insights may well be elicited in individual interviews, the above examples suggest that, by allowing access to shared performances, joint interviews offer some analytic advantages: they provide credible evidence that these are shared practices; and the couple's interactive work helps to elicit elements which are more likely to remain invisible in individual accounts.



### ***Material practices***

Joint interviews, then, may have some advantages over individual interviews in that the interaction provides analytical purchase on accounts of how, and which, knowledge resources are brought into play in making decisions. Beyond this, we also suggest that joint interviews can contribute to evidence on material practices related to health care decisions. It is a truism of qualitative methodology that we cannot infer what people do from what they say they do. Joint interviews, however, may mitigate this weakness, by providing both direct opportunities to observe some practices, and by creating an interactive environment which allows some analytical purchase on the credibility of accounts of practices. This interactive context is one in which the narratives of the two participants intersect. These intersections can be seen as falling into three types: the two interviewees' accounts sometimes confirm one another, sometimes add to and complement each other, and sometimes contradict each other.

#### *Confirmatory accounts.*

At first glance, confirmation seems very reassuring: surely if interviewees agree then it must be what they actually do? However, as Warin et al [2007] warn in their defence of a post-positivist approach to dealing with multiple narratives from household members interviewed separately, there is a danger of being "seduced into a realist epistemology" in this way, and forgetting that the interview itself is a presentation, which may involve the performance of consensus. This warning seems especially pertinent for joint interviews. Here, for instance, Janet and Vic provide a confirmatory narrative.

Janet (J): It has become a way of life now

Vic (V): It has become a way of life. I mean ok, I mean I think I've missed the night pills once, never missed the morning pills

I: How do you actually set about remembering them?

V: I do it the night before, really.

J: It is a ritual, every night he gets his pills out for the morning [*laughs*].

V: A ritual ...

J: Well, you are an organised person anyway so organising pills is the way you are.

If these utterances are treated as simply guides to what Janet and Vic think and do, then the repetitions and echoes can be seen as triangulation, strengthening the validity of inferences about, for instance, the “ritual” they have established to remember taking pills. However, clearly this would ignore the presentation work of narrative construction of a shared account which has its own momentum. Within such a strong consensual story, instances which do not fit the picture may be overlooked and not mentioned. Janet’s use of stock phrases (“a way of life” and “a ritual”) is echoed verbatim by Vic, suggesting an account they have given before, or at least one that is rooted in a long-established shared way of describing the world. This solidly-ingrained shared performance is one in which Janet shares not only in telling, but also in performing, as she contributes to Vic’s presentation of himself as “a highly-organised man”. Such a performance may make the times that Vic actually forgets his tablets pass as aberrations which seem unworthy of mention in telling the story, and indeed neither the interviewer nor the participants return to the atypical “once only” missing of the night pills during this interview. Thus, the very fact of having two confirmatory accounts, rather than just the one from an individual interview, does not necessarily add to the validity of data. There is perhaps a temptation to exaggerate claims about “unanimous” joint interview data as a valid source of information about what people do, when such accounts might at times be better read as “idealised or conventional” [Valentine, 1999] shared accounts of their behaviour.

*Complementary accounts.*

Where the two partners’ accounts do not merely echo but complement one another, this may strengthen the credibility of inferences made about what they do, by adding precise details. For example, the shared account in the next excerpt strengthens the credibility of two particular inferences: that Mike and Eileen really do take their pills in the way described, and that doing so is one of their shared household routines. These strengthening effects of joint interviewing are underlined in this case because, as well as complementing Mike’s account when invited, and adding extra detail, Eileen actually reminds him about his pills during the interview, which took place at about 7 o’clock.

Mike (M): We have our breakfast and then we take our tablets, don’t we.

Eileen (E): You have to wait though because you have to eat with a lot of tablets, and we have our breakfast and we take our tablets, and I do my injection, then we go all day and then, at night-time before we go to bed we take the other one, that's all. Quite easy.

M: I take warfarin at 6 o'clock don't I, every night.

E: Yes he takes his warfarin at 6. Have you had them yet?

M: Yes I have taken them, yes.

Directly witnessing a material practice in this way was unusual in our dataset, although Torgé [2013] reports a similar example, when one participant helped the other to drink some water during the interview. However, even without this bonus of observational data, the couple's complementary accounts strengthen the tentative light that interview data can shed on what they actually do, compared to using an individual interviewee's account as evidence about her actions.

#### *Contradictory accounts.*

One of the most fruitful kinds of data from joint interviews is provided when the two interviewees contradict each other, particularly where contradictory claims are negotiated by reference to shared experiential evidence. In this excerpt Gill directly challenges Simon's account of his own reliability:

Simon (S): So I try and take one in the morning before breakfast on an empty stomach, and then one in the afternoon, before I have anything to eat

Interviewer (I): How do you remember?

S: Well I just take it, as a matter of course, it comes in naturally now –

Gill (G): I remember! I get it ready for him, I get all the tablets, normally, ready

I: For the pair of you?

G: Yes. Cos I've got them – they're all lined up in the drawer. So I know, roughly, I just go through them and put them all out.

If this was an individual interview with Simon, it might be tempting to take his account as a close match with what he actually does, although his airy "it comes in naturally" would inspire less confidence than a more detailed description such as Gill gives. This temptation may of course still be misleading as regards the version of events offered

by the shared account, but in this relatively informal setting it seems unlikely that Simon would not have contradicted Gill if he disagreed with her, as she did him. By offering them the opportunity to contradict each other, joint interviewing strengthens inferences about interviewees' practices.

## **Discussion**

The opportunity to observe shared storytelling is a widely-documented advantage of joint interviewing. [Bjornholt and Farstad, 2012; Radley, 1989; Sakellariou et al, 2013; Torgé, 2013]. In health research, this opportunity has largely been used to shed light on living with chronic illness; we suggest that it can also be used fruitfully in other arenas of health and health care. We highlight two specific strengths of joint interviewing. First, it offers advantages over individual interviewing for studying the resources people draw on to inform their decisions about health practices. Second, using joint interviews may mitigate some of the weaknesses of interview data as a source of credible evidence about practices themselves; these practices include those that may be directly performed in the interview, such as joint decision-making, but also practices that are not directly observed, such as taking pills. These analytic advantages of joint interviewing arise from access to interaction between the two participants.

Morris [2001] points to the ways in which her joint interviewees made tacit knowledge explicit in order to clarify their account to an outsider, thereby shedding light on what they chose to mention and the discourses implied by these choices. In the same way, we have identified how participants in our interviews did some useful interactive work, in prompting, clarifying and making explicit (for the outsider-interviewer) the assumptions and tacit discursive frameworks which make their partner's accounts intelligible. It is not that this work does not happen in an individual interview. With sufficient rapport, and the appropriate use of prompts, it is possible for the interviewer to invite the interviewee to expand or reflect on responses, or to challenge the assumptions made in responses. There are limits, however, to how far it is possible to do this, particularly in a one-off interview. To directly challenge accounts, in the ways illustrated in some of our excerpts, would risk disrupting an interview entirely, and asking "what exactly do you mean by that?" too

often risks abandoning the minimal requirements of successful interview interaction. Partners, however, can and do conduct some of this work for the interviewer, in a similar way to participants in larger natural group interviews. This is a well-documented strength of natural groups for studying how assemblages of largely-tacit knowledge and values coalesce in decision making about health (see for instance Green, Draper and Dowler [2003]; Kitzinger [1994]). There are far fewer examples of using joint interviews in this way.

Another similarity between joint and other natural group interviews is that interaction both between the participants and with the interviewer seems likely to be more naturalistic than in a one-to-one interview. This is the basis for our second claim: that analysing the interaction between participants may provide a way of strengthening the credibility of inferences about practices, particularly those which take place during an interview. This “naturalism” is a seductive assumption, with its suggestion of direct and privileged access to how people talk to one another (and influence one another) in the kinds of everyday settings in which health care decisions are made. Manzo et al [1995], for instance, in their study of stroke patients and spouses, suggest that because they interviewed people at home in couples, their data is likely to resemble “casual, ordinary talk”; and Morgan et al [2013] write of dyads “disclosing in-depth thoughts”, stating that “the only difference from an ordinary conversation is the presence of a moderator who asks questions and probes portions of the conversation”.

Such claims to naturalness need to be problematised; the creation of shared narratives, whether confirmatory or competing, is clearly a situated performance, in which the participants are, as Morris [2001] puts it, invited to “represent themselves not as individuals, but also as concurrent participants in a relationship”. For Morris [2001] the joint interview combines the performance elements of a group setting with the intimacy of an in-depth individual interview. In our data, there are suggestions of perhaps greater “intimacy” than might be generated in an individual interview, with participants clearly at ease co-creating narratives. As the couples take turns to add detail, and move the story along themselves, there is (at a practical level) less need for the interactive form of a question-and-answer interview format. So the joint interview may, structurally, resemble everyday conversation, but that does not imply that there

are not performative aspects to the interaction, as there would be in any other social situation. As Warin et al [2007] show, participants' performance is shaped by their positioning of the interviewer in relation to the research topic; this as true of joint as of individual interviews. Thus assumptions about naturalness require reflexivity, even when studying practices which are observable during a joint interview. For "off stage" practices like pill-taking, joint interviewing cannot negate the obvious point that people do not do exactly what they say they do; nonetheless we suggest that the way the two interviewees' accounts intersect can make joint interview data a stronger basis than individual interviews for inferences about material practices.

The central question of our project – how people make decisions to take statins – is, we have suggested, one which entails recognition of the distributed nature of such decisions. As Rapley [2008] has pointed out, decision-making may entail cognitive processes that can be explicated to some extent in interviews, but also interactive practices which are widely and unpredictably distributed in lived space: seeking information; talking to others; communicating in the doctor's surgery; discussing implications with a partner; and material practices such as typing search terms into a web browser or managing the routines of regular pill-taking. It would not be possible to observe all of these contingent and dispersed practices; and even where some can be observed, the act of observation, providing an audience, generates a performative space.

It is precisely around these kinds of research question that the joint interview may have particular strengths. The joint interview is a space in which co-production of a public narrative is directly performed, and practices such as assessing knowledge sources, resolving conflicting advice or developing a coherent rationale for action [Bjornholt & Farstad, 2012; Radley, 1989; Sakellariou et al., 2013; Torgé, 2013] can be observed by the interviewer. Strong [2006/1979] gives an account of the relative merits of observation and interviews as sources of data about the "rules" people follow in everyday interactions. He points out that such rules are hard to study using observation, because they are generally tacit, being made visible only occasionally, for example when they get explained to an outsider or disagreed over. In interviews, on the other hand, rules may be spelt out upon request, but it is impossible to know to what extent they actually get followed. A joint interview offers opportunities to

observe interaction between the participants which may offer clues to the tacit rules being followed, while also allowing the interviewer to steer this interaction towards the focus she is interested in. Thus, as well as combining some advantages of both focus groups and individual interviews, as Morris [2001] suggests, joint interviewing may also be seen as a useful hybrid between observing and interviewing.

## **Conclusion**

Joint interviews, using dyadic approaches to analysis, have been widely used in studies of couples living with illness. We show how they can also add value to studies of topics such as making health decisions. Specifically, we suggest that shared storytelling, to which joint interviews offer access, helps explicate what is often tacit knowledge. We also suggest that, where the research question relates to everyday health practices shared by the participants, joint interviews may mitigate some of the weakness of interview data for providing evidence about what people do. These advantages of joint interviewing rely upon three features: the two participants being interviewed together, a dyadic approach, and some prior relationship between interviewees; these strengths are likely to depend upon the existence of a dyad which not only has a shared experience, but which also has some pre-existing identity as a dyad in relation to the research question. To facilitate further exploration of this area, it would be helpful if authors explicitly specified these features of their method.

In our example, the participants were all married couples, invited to take part in a study on the decision to take statins, and it remains to be demonstrated how far these advantages relate to other relationships or research questions. We suggest that when the research question relates to some phenomenon that is empirically a shared one, such as decision-making within households, joint interviewing may be particularly appropriate.

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## **Methods used in generating and analysing data**

The process of generating the data and analytic accounts presented in the Findings chapters of this thesis used elements of a grounded theory approach: close coding of the data from a first small group of interviews was used to inform selection of the next group and to refine the questions asked, and this cycle was repeated, generating more abstract stories through a process of constant comparison both within the data and within several different literatures. The task of this section of the Methodology chapter is to give enough detail about the interviews and analysis to underpin credible claims to validity of the stories told in later chapters, and to identify the limitations of these claims as well as their strengths – reflexive discussion of these limitations and strengths is a central feature of the following description of the methods themselves, rather than constituting a separate section of the account.

### **The interviews**

The thesis draws on data from 43 participants in total, some interviewed in individual in-depth interviews, and some in couple interviews. They all lived in or near a medium sized town in East Anglia and were aged over 50, and they were not my own patients. The individual chapters and papers in the thesis draw on various sub-samples of these participants. All the participants and the pseudonyms used in the thesis are listed in Appendix B, which also includes some demographic details. The tables include a brief account of the reason for selecting each of the four groups interviewed; these reasons each emerged from analysis of the previous ‘batch’ of data, which highlighted questions unanswered by these completed cycles of interviewing and analysis. As well as questions requiring a different kind of empirical data, and hence directing recruitment of the next group of interviewees, each cycle also directed attention to lines of theoretical enquiry, informing further discussion with colleagues and exploration of the literature. This iterative process of discovering new areas of pertinent scholarship is mirrored by the way the literature is referenced and discussed in every chapter of the thesis.

I conducted all the interviews, then transcribed the first few myself and had the rest transcribed for me, although I then listened to the recording myself so as to correct any transcription errors and pick up anything the transcribers had missed. Although I did not attempt to use non-verbal features of the recorded data in any formal way, I did note a

few such features that seemed particularly striking, such as laughter, or the whisper in which an interviewee corrected something her partner had said, tacitly appealing to me (as another middle aged woman) to agree that his statement was typical of ‘the kind of thing men do say’. I also took notes about some material objects that interviewees showed me, such as pill boxes and lists of medications. Some of these objects turned out to contribute to the analysis, supporting inferences based on what people said. For instance an interviewee talked with no apparent discomfort about her regular blood tests as something done to her, and their results as being of no interest to her but instead belonging to the healthcare team, suggesting a willingness to present herself as reliant on a lot of help to care for herself; this inference (about both the material practice itself and her relation to it) was reinforced by her vague gesture towards the book in which the results were recorded, sitting alongside the testing kit, across the room and completely out of her reach. Thus, although not attempting to claim that this constituted an ethnographic approach, I did incorporate some observational notes from interviews into the body of data drawn on for analysis.

This use of observational data was one feature of the interviews that emerged and evolved over the course of the interviewing stage of the project, in response to a growing awareness of its value. Another feature that developed in this way was the interviews’ character as informal conversations. This resulted partly from a deliberate move to distinguish my own approach as clearly as possible from the approach I am used to when visiting patients at home, as a GP. However, some basic interviewing skills, such as active listening, open questions and a non- judgemental approach were clearly transferable from GP consultations to research interviewing, so that in some senses I was not a novice interviewer. Other GP habits were arguably less appropriate and perhaps unhelpful; for instance, although expressing sympathy or concern when people talk about things that distress them is presumably well within the bounds of approved practice for a research interviewer, I also say ‘Good’ (when told that people are feeling better now, or have found a pill that suits them) in a way that hints at it being my business to be pleased, as it is in my GP role. This is one of several small points highlighted by reviewing the early recordings and transcripts, and so in later interviews I worked to try to correct them. I also worked throughout all interactions with participants to avoid offering a ‘medical’ opinion or advice, responding to occasional requests by suggesting that they should talk to their own doctor. This cannot completely

have prevented interviewees' participation from influencing their health beliefs or behaviours, just by drawing their attention to issues they may not have thought or talked about much before; highlighting this effect, Hitchings [2012] cites it as a potential bonus of interviewing people about their practices. In the context of interviews about medication practices, however, it would clearly have been unethical for me as a researcher to risk confusing people or affecting their relationship with their GP, and unethical for me as a doctor to treat them as patients with inadequate knowledge of their medical history.

Almost all interviewees knew I was a GP. Just a few had not realised, or had forgotten, something which emerged when they asked me why I was doing the research, often at the end of the interview; when I mentioned being a doctor, a few people were surprised. The decision to introduce myself as a GP when recruiting interviewees was deliberate: it was a reassuring opening, prefacing the suggestion that I could come and talk to them at home if they were happy with that (all were except one); and it also seemed to me slightly dishonest to conceal it. On the other hand it constitutes a significant limitation in two ways; first, people may have talked differently to someone they did not know was a GP, and second, someone who really wasn't a GP may well have conducted the interviews differently, following leads I ignored or overlooked or avoiding avenues that struck me as interesting because of being a doctor. Regarding the first of these concerns, about people talking differently to a doctor, a reassuring feature of several interviews was the amount of criticism people expressed both about specific doctors and the medical establishment in general, although of course they may have been even more outspoken had they not been speaking to a doctor. However, it seems quite likely that the accounts given of 'medical' entities, such as cholesterol, blood pressure and heart problems, were shaped by speaking to a doctor; just one interviewee gave a detailed explanation of what cholesterol meant, although he may have wanted to demonstrate that he knew, rather than having forgotten that I would know already. The elision of such details from most accounts is considered within a discussion of the nature of 'reification' in this context, in the paper in Chapter 4, a discussion which acknowledges the possibility that people might have offered detailed explanations more readily had they not been talking to a doctor.

Regarding the likelihood that a non-doctor would have conducted different interviews, this is hard to assess, particularly for myself, and sins of omission are likely to be harder to spot than sins committed, so it is safest to assume that there are many differences that I have failed to identify. However, one problem was discernible in the early interviews (combining both these types of sin): a tendency to steer the conversation too firmly, thus closing down ‘diversions’ from the path specified by the topic guide. This realisation prompted a significant shift from my medical interviewing approach, where the dual constraint of time and of the need to balance the patient’s choice of focus with the doctor’s tends to produce very different data. Two moves were required to achieve this shift. First, the topic guide was shortened, listing fewer and less detailed points and removing the emphasis on deciding; as discussed in an earlier section, asking questions like ‘How did you decide..?’ did not prove fruitful in the early interviews, and raised analytic concerns about eliciting unhelpful rationalisations and about finding only what you set out to look for. Second, the interviews themselves became more informal, moving closer to a narrative approach within which I asked the minimum of questions to encourage participants to tell the story they chose.

This informality was particularly easy to achieve because of two other personal characteristics: I am middle-aged, and live in the same area as the study participants. As well as helping participants to feel relaxed, seemingly comfortable chatting about themselves and their families, this ‘insider’ status may have constituted a disadvantage in some respects, by reducing the perceived need to give a detailed account of things that were taken for granted between us. This disadvantage follows from Strong’s [2006/1979] point that tacit rules ‘are spelt out only in special circumstances, as ... for example... when outsiders are present’ [p185]. For example, the joking whisper to me about her partner, mentioned above, might have been usefully expanded by the participant for a younger or male interviewer, or for one who did not seem like a local. This is essentially the same limitation as the one about people not explaining cholesterol to a doctor, but in this case it seems an inevitable price to be paid for its obverse: it seems likely that people will talk in a more relaxed way to an insider, thus generating a richer narrative which offers more analytic purchase.

However, this additional purchase needs to be handled with care to avoid forgetting Bourdieu’s [1990] warning that ‘participant observation’ is a contradiction in terms



which makes it tempting to overlook ‘the real relationship of the observer to the observed and its critical consequence for scientific practice’ [p34]. My earlier reference to the interviews as informal ‘conversations’ risks leading into this trap, obscuring the fact that the interviewer is ‘play[ing] the game as a game while waiting to leave it in order to tell it’ [p34]. Although using a recording device makes it easier to forget about ‘waiting... to tell it’, separating participation from observation to some extent, the requirement to obtain useful data (both by steering the interaction at times and by observing non-verbal aspects) nonetheless divides the interviewer’s attention and so shapes and constrains her participation. This is another way in which research interviewing has some similarity with conducting GP consultations; Neighbour’s [2004] book for GPs about the challenge of dividing one’s attention refers to ‘the inner consultation’ that must proceed in parallel with the consultation the patient sees.

A further consequence of my medical background became apparent at a later stage of the research, and relates to my decision at the outset to collect a small amount of medical background information pertinent to assessing cardiovascular risk, at the end of each interview. For doctors there is a highly salient difference between primary and secondary prevention of cardiovascular disease: prescribing risk reducing medication such as statins for secondary prevention, for instance giving them to someone who has already had a heart attack, tends to be endorsed far more strongly and unanimously than prescribing for primary prevention, to reduce the risk of a first heart attack. So I approached the analysis expecting to find very clear differences between participants who had and those who had not had heart attacks; this expectation is problematised within discussions of how pill taking gets legitimated, in Chapters 4 and 5.

## **Analysis**

As this last example (about primary and secondary prevention) shows, being a doctor affected the research through influencing not only the data generation but also the analysis. At the outset, reading and discussion with colleagues and advisors helped me problematise and eventually discard two related assumptions very prevalent within the biomedical community: a positivist ontology, and a conception of research as an enterprise whose goals could and should be specified at the start. A shift from this position led to the open ended exploration described here, with its iterative construction of a plausible story whose topic and shape cannot be determined in advance but only

inferred by means of successive cycles of data generation and analysis. The perception (discussed in the first half of this chapter) that interviews constitute situated encounters that generate data, rather than opportunities to ‘collect’ implicitly context-neutral data, represents one result of this shift away from the biomedical stance I started with.

Another change in stance near the beginning of the analysis made me aware of the limitations of low-level thematic coding, a basic analytic approach that closely resembles the process used within a GP consultation to build a quick picture of what is going on. Here, however, a less dramatic shift from the medical model was needed: moving on to use constant comparison and generate a more abstract, theoretically informed account that remains grounded in the empirical data is not very dissimilar to moving from the individual patient’s story to a list of likely diagnoses, using comparisons both with knowledge about this and other specific patients in the past and with theoretical, ‘evidence based’ knowledge. Having to make these shifts drew my attention to interesting parallels between the practices of knowledge construction enacted within different communities, raising questions about power and expertise that are addressed in the discussion chapters at the end of the thesis.

Later in the research process I used my familiar ‘biomedical’ assumptions in analysis, first contrasting them with those indicated by participants in connection with prevention and the role of statins (in Chapter 4); then focusing on the tension between ‘medical progress’ and ‘medicalisation’ in Chapter 5, identifying ‘progress’ as the dominant framing within the biomedical community; and then comparing the deciding process implicit in medical talk about shared decision making with the framing central to the story I tell in Chapter 6, about deciding as a social practice. Using a body of data as the starting point for three different lines of enquiry is an approach modelled by Halkier [2011], in a paper describing three different ways of building analytic generalisations using data generated by a study about food. This approach also builds on Strong’s [2006/ 1979] recommendation that qualitative researchers should aim to construct ‘a plausible story’ about what is going on; this recommendation seems compatible with constructing several plausible stories grounded in one body of data, as I seek to do here.

Although I frequently use the metaphor of stories and storytelling to frame and present my findings, I do not adopt either of the approaches that these words most commonly signal: this is not an account of a narrative analysis, nor do I adopt Frank’s [1995]

approach, taking stories as the unit of analysis. Strong, however, uses descriptions and discussion of some of his own work to illustrate that there are other ways of using the ‘story/ storytelling’ metaphor, both in describing what interviewees do and produce, and in describing how a qualitative researcher might use interview data. Both these uses are visible throughout this thesis. For example, the paper included in this chapter, about some of the advantages of using couple interviews, uses Strong’s approach to frame couples as co-constructing a story that they are comfortable to present to themselves and to the interviewer; in the paper in Chapter 6 I suggest that constructing such a story constitutes making a decision; and the first Discussion chapter, Chapter 7, highlights the way cholesterol is cast as a character in several different everyday stories, and suggests that this multiple casting helps people to build usable knowledge about it. Viewing the thesis itself as a story helps in two ways. It helps to clarify the thesis’ structure, as a continuous narrative with a beginning, a middle, and an end. It also helps to see that conceptual elements within the narrative, such as need, certainty or legitimacy, function like characters in a story: some are more major or persistent than others, and there are complex interactions between different characters.

## **Summary**

The methodological choices described and discussed here are presented biographically, starting with some of the approaches considered early in the project and explaining why these were rejected. Instead of using these early approaches, I decided to frame this as a study of social practices; to use a normative conception of ‘practices’; and to handle interviews as situated performances, using them both as a source of clues about tacit resources participants draw on and moral imperatives they negotiate, and as an opportunity for observation. The advantages and potential pitfalls of this way of using interview data are summarised here and discussed in the paper included in the chapter. This biographical account emphasises that my methodological approach evolved through an iterative process as the research proceeded, shaped by the practical experience of doing research, and by interactions with experienced researchers, as well as by theoretical knowledge about qualitative research methodologies which I obtained from reading and lectures. Towards the end of the thesis, in Chapter 7, I shall return briefly to this process of learning how to do qualitative research, casting it as an object of study in itself, a useful example of knowledge construction and of the way

practitioners develop expertise. Then in Chapter 8 the biography turns full circle, drawing on the study findings to consider the pragmatic biomedical puzzle that prompted the initial research question.

The last section of the chapter describes the methods used in data generation and analysis; in this reflexive account I consider some of the strengths and limitations of the research project, particularly those resulting from my being a GP. Detailed information about the interviews is provided in two appendices: Appendix A includes the topic guides used in the interviews, and Appendix B presents information about participants. Brief summaries of this information appear in each of the Findings chapters, an unavoidable drawback of writing a thesis that incorporates several papers submitted for publication.

## Chapter 3: What does it mean to ‘need’ statins? Using quantitative information

*Kathy: ‘Most of the people I know who take [tablets] really really need them....They do react badly if they don’t [take them]’*

### Introduction

The next four chapters of the thesis build a picture of the way people who are offered statins come either to take them or to decide to decline the offer. The sequence of these chapters reflects the iterative analytic process used to move from a collection of empirical data to a theoretically informed account of what is going on; hence these first two chapters present findings generated early in the process in response to the research question with which the study began: ‘how do people decide about statins?’. The assumption that ‘deciding’ (implicitly a cognitive process, although not necessarily a rational one) was a central character in a story about how people come to take statins was left unproblematised at this stage of the analysis, as it is throughout and even beyond the biomedical community, so this chapter is about medication decisions. To construct a thick description of the way people account for such decisions, early analysis of the study data centred on a highly salient feature of these accounts: many participants talked about *needing* medication, either about taking it because they needed it or about avoiding it unless it was really necessary. Each of these first two Findings chapters incorporates a paper that explores the way ‘need’ is constituted in the context of preventive medication.

A ‘common sense’ assumption widely visible in the data is that tablets a person takes to make her better when she is ill are tablets that she ‘*really need[s]*’. Kathy, the participant quoted above, goes on to list the many tablets she herself needs to take, and identifies herself as one of those who ‘*react badly*’ if they do not take them. This assumption does not help to address the puzzle considered over the next two chapters, concerning the way people come to decide that they need to take regular medication while they feel well. In this chapter, the paper presented describes the health information that participants use to assess their need to take medication; the paper in Chapter 4 offers a more theoretical account of the way people use this information to construct and present an account of the health problem or ‘condition’ which might

require treatment. In both these papers, ‘a condition’ appears as a slippery character which has an inherently circular relationship with ‘needing’ medication: knowing one needs medication is a commonly indicated way of knowing one has a condition, but having a condition is a widely accepted reason for taking medication. This relationship is illustrated by an excerpt from an interview with a couple, Don and Mary. Don has been talking about his preference for using exercise and diet rather than medication to stay healthy, and Mary queries what he says about wanting to avoid medication. The underlining within this excerpt indicates Don’s spoken emphasis, which highlights the salience of the distinction he is making:

*Mary: But if you have a condition you would –*

*Don: Well if you have a condition, well that’s right . . . we’ve had more than one... episode, haven’t we, Mary, of where you needed medication*

To understand what people mean when they talk about ‘needing’ medication, it is necessary also to understand what constitutes ‘a condition’. The paper below compares two possible candidates for ‘condition’ status: having abnormal test results and having a high risk level. Where these potential ‘conditions’ are discussed, both in the data and in biomedical guidelines, numbers are frequently used to describe them and to specify how they function as goals or as triggers for action.

### **Using (or not using) quantitative information to account for medication decisions**

From a biomedical perspective statins epitomise preventive medication: clinicians prescribe them purely to reduce the risk of future illness. From this perspective, therefore, saying that someone ‘needs’ statins means that by taking them she will reduce her risk of future cardiovascular disease by a worthwhile amount. The amount of reduction that is ‘worthwhile’ is determined at two levels in a publicly funded health system like the NHS: health policies are informed by the cost effectiveness of the preventive intervention, and then the individual assesses whether the intervention is worthwhile to her. In making this assessment, individual patients are helped by clinicians to consider their own personal circumstances and preferences alongside the evidence based recommendations of the policy makers. Some of these recommendations to take statins are given to individuals within groups defined on the basis of qualitative information about their past medical history; for example, anyone who has had a heart attack is advised to take statins. For another large group of individuals this

recommendation is made on the basis of quantitative information, particularly cholesterol levels and risk estimates. It is for patients in this group that clinical guidelines state that clinicians should communicate quantitative risk information so as to facilitate shared decisions about statins; computer software in every GP's consulting room combines information about cardiovascular risk in the population with information about the individual patient to produce a personalised estimate of that individual's likelihood of suffering a heart attack in the next ten years, and clinicians are enjoined to tell the patient this estimate.

Comparing different ways of formulating and presenting a personalised risk estimate to its owner is the topic of an extensive body of research. To those engaged in this 'risk communication' research, it is axiomatic that patients should be encouraged to engage in informed shared decision making about their treatment, that being 'informed' includes being given quantitative risk information, and that patients will use this information once they have been given it and helped to understand it properly. Trevena et al [2013], for example, begin their summary of best practice in risk communication by stating that 'patients have a more accurate understanding of risk if probabilistic information is presented as numbers rather than words'.

The value of this understanding is taken for granted. However, the implied assumption, that patients make use of probabilistic information provided they understand it, is called into question by Gale et al's [2011] finding that even when people did understand what their personalised risk estimate meant, they did not use it in making up their minds about statins. This finding challenges the central goal of the risk communication project: to influence decision making by promoting understanding of quantitative risk information. The study presented in this thesis, too, finds that risk information is very seldom used to account for medication decisions, and goes on to consider why this might be. Complementing Gale et al's finding that understanding information does not necessarily lead to using it, the paper which follows highlights the finding that not understanding quantitative information does not prevent people from using it. Indeed, participants in this study frequently use such information to explain their medication decisions despite seldom indicating that they understand what the numbers represent, and quite often despite indicating explicitly that they do not understand. Rather than focusing on the negative finding that people do not use risk estimates, the paper offers a description of the way they do use other kinds of quantitative information in talk about

statins. This description builds on an initial analysis of the role of numbers in the data, which is summarised here.

### **Using numbers**

The data generated in my interviews are full of numbers; an early analytic goal was to understand what they are used for. As well as test results, the focus of discussion in this chapter, numbers are used in the data to describe several other things, such as health behaviours (for example number of vegetables eaten daily), time (for example the duration of an illness) and drug dosages. In all these contexts, measurement is almost always at least comparative, involving some ranking rather than just a nominal distinction such as 'green or blue'. Examples of a number used purely as a name are rare here, and appear to be an analytic dead end in the context of this study: for instance, describing the supplements he takes, Simon says *'I only take, the omega, omega 3, 6 and 9. When we started taking it there was 3 and, I used to take 3 on its own'*. Other apparently nominal uses of a number turn out on closer examination to be likely to carry a significant comparative element. A few participants describe themselves as having Type 2 diabetes (a purely nominal use of '2', to a doctor), but Don's comment exposes the way he understands this problem, ranking it as less severe than Type 1 diabetes: *'diabetes Type 2, if it's not ... monitored it can ... spiral into Type 1'*. Similarly, Geoff describes what sounds like a nominal use of numbers to identify the type of statin tablet he needs to borrow from one of his friends – in this excerpt the numbers could plausibly be replaced by three different colours: *'I asked around, ... could anybody spare me a statin or two. And a couple of them said Yeah are you 20, 40 or 60?'* However, this interpretation is weakened by the likelihood that Geoff understands these numbers to represent a sequence of increasing doses, a likelihood strengthened by finding that several other participants explicitly indicate that a higher dose of statin means a more powerful effect: *'he said well, we'll double the dose, since you're on a minimum dose, and see if we can get it [cholesterol] down a bit more'*. Within the analysis presented here, then, numbers are used for comparisons – with other people, with one's past self, or with an accepted threshold level defining normality or acceptability.

Numbers are particularly suited to being used to make comparisons, because they are relatively stable and hence portable across both time and space; although the ways measurements are made and the yardsticks against which they are calibrated may well



be subject to some variability between contexts, the meaning of a number is nonetheless likely to be more reliably reproducible in a variety of contexts ('constant' or 'objective', in biomedical terms) than a verbal description like 'very high'. Additionally, the respect widely accorded to numbers in the biomedical community has leaked out to inform a more widespread respect; in her account of the way people collect and use largely quantitative information about their own body obtained by mHealth or mobile self-tracking devices, Lupton [2013] critiques the way 'the lure of the "numbers"' to adherents of self tracking is informed by the 'accepted concept of them as...scientifically neutral'. In the data presented here, this acceptance is echoed by a participant's reference to numerical test results as a good basis for deciding whether to take medication because they are '*hard evidence*'; it is also indicated by the prevalence and salience of quantitative test results in the data, although this may have been increased by participants' awareness that the interviewer was a doctor.

Given this respect for and frequent use of numbers, and the biomedical framing of statins as prescribed to reduce risk, the paucity of numerical risk estimates in the data is a surprising finding. The paper that follows takes the contrast between test results and risk estimates as a starting point from which to examine the way numbers are used to explain medication practices, and to inform a hypothetical explanation for the observation that participants do not use quantitative risk information to account for their medication decisions.

## **Paper 2: Using quantitative risk information in decisions about statins: a qualitative study**

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## **Abstract**

### **Background**

A large literature informs guidance for GPs about communicating quantitative risk information so as to facilitate shared decision-making. However, relatively little has been written about how patients utilise such information in practice.

### **Aim**

To understand the role of quantitative risk information in patients' accounts of decisions about taking statins.

### **Design and Setting**

This was a qualitative study, with participants recruited and interviewed in community settings.

### **Method**

Semi-structured interviews were conducted with 34 participants aged over 50, all of whom had been offered statins. Data were analysed thematically, using elements of the constant comparative method.

### **Results**

Interviewees drew frequently on numerical test results to explain their decisions about preventive medication. In contrast, they seldom mentioned quantitative risk information, and never offered it as a rationale for action. Test results were spoken of as objects of concern despite an often-explicit absence of understanding, so lack of understanding seems unlikely to explain the non-use of risk estimates. Preventive medication was seen as "necessary" either to treat test results, or because of personalised, unequivocal advice from a doctor.

### **Conclusion**

Our findings call into question the assumption that people will heed and use numerical risk information once they understand it; we highlight the need to consider the ways in which different kinds of knowledge are used in practice in everyday contexts. There was little evidence from this study that understanding probabilistic risk information was a necessary or valued condition for making decisions about statin use.

### **Key words**

Decision Making, Shared; Risk; Prevention; General Practice; Statins, HMG-CoA.

### **How this fits in**

Much is written about the best way to present quantitative risk information to patients, as clinicians are encouraged to do. Less research considers how such information is utilised in practice. In our interviewees' accounts of their decisions about statins, risk estimates were hardly mentioned and never described as influential. If replicated elsewhere, this raises the question: should communicating quantitative risk information remain a central component of endeavours to facilitate shared decision-making?

## **Using quantitative risk information in decisions about statins: a qualitative study**

### **Introduction**

Statin prescriptions for those at high cardiovascular risk have widely been seen as an important contributor to reducing the population burden of heart disease (1). Such strategies rely on general practitioners identifying those at higher risk, and communicating the benefits of medication to patients. A large body of research now addresses how to communicate risk information (2), and a growing evidence base is emerging on how best to present patients with quantitative information about risk in general practice (3-6). This evidence suggests that information about risks is best presented quantitatively, as event rates (2), although general practitioners may prefer qualitative rather than quantitative presentations of risk (3). Evidence that presenting numeric information to patients improves risk comprehension (4) has influenced good practice guidance for developing decision aids for patients (6).

Most evaluative research about risk communication formats has used accurate recall of information and comprehension as end points (2, 4, 7). There is less research, though, on how such cognitive risk understanding is used in practice. That is, once people have the information and comprehend it, how will they use this knowledge to make decisions? Patients' general views of preventative medication use have been widely researched, with reported reservations about taking hypertensive medication (8) reflecting reservations found for long term and preventative medications in general (9). In the light of recent interest in risk communication, there is a need for more research on the specific question of what use is made of quantitative risk information in decision-making about preventative medication. This paper addresses this question through analysis of qualitative data generated in a study of how people make decisions about taking statins.

### **Methods**

#### ***Setting and participants***

Thirty-four participants aged over 50 were recruited and interviewed face-to-face in community settings, most in their homes, in East Anglia between 2011 and 2013. Invitations to participate were made through community groups such as lunch clubs and an exercise class and snowballing from initial participants to identify those offered statins. All participants had been offered a statin for either primary (N=17) or secondary prevention (N=17); over half (22) were currently taking statins. Participants were aged between 53 and 87.

### ***Data generation***

Twenty two participants were interviewed in couples, and twelve in individual interviews. This allowed us to draw both on the advantages of pair interviews, which generate less formal accounts than are often generated in one-to-one interviews, providing some access to how participants talk within the everyday contexts within which decisions are made; and on the advantages of more private interviews, which allow participants to discuss issues that might be sensitive within relationships (such as fear of future ill health). All interviews were conducted by the first author, who introduced herself as a local GP doing a research project which was separate from her practice work. None of her own patients were invited to participate. All interviews were recorded and transcribed verbatim. Interviews were semi-structured, using a brief topic guide, and lasted between 23 and 87 minutes. Prompts included questions on: participants' state of health; where their knowledge about health came from; how they looked after their health; use of medication; and deciding whether to take statins.

### ***Analysis***

Analysis drew on elements of the constant comparative method (10), beginning with in depth line-by-line coding of early data, and comparisons both within the data and with the literature to generate provisional explanations. Coding and memos were recorded using multiple Word documents. Codes were refined by relating them to subsequent batches of data and further reading of relevant literature, in an iterative process aiming to build a robust and potentially generalisable account: "a plausible story about what is going on" (11). Throughout this process, rigour was increased by regular discussion with colleagues about coding decisions and analytic direction. In this paper, all names are pseudonyms and identifying material has been removed.

### **Results**

Initial thematic analysis elicited a surprising fact: although people's accounts were full of numbers describing health or health behaviours, there were almost no instances where numbers were used to talk about risk or prevention. Further analysis was directed towards explaining this contrast, by comparing the way numerical test results were used with the way risk and prevention were talked about.

***Using quantitative information: “magic numbers”***

Participants’ accounts contained varied and frequent references to numbers related to health and health care, including numeric indicators of weight, blood pressure, medication dosage and blood test results. A common use of numbers was for making comparative assessments in relation to (for instance) their past self, or other people:

*Peter: All I know is my blood pressure is a lot lower than it used to be, because it used to be 180/90 ... and is now 118/60*

A second use of numeric values was as triggers for action. Here, participants used specific numbers as thresholds or goals when talking about the way they took decisions about health behaviours or health care use:

*Larry : Since I’ve been on the statins it’s down to about 2 or 2.5, which is where they want it to be with, my situation*

*Debbie: They said it was about 6.9 and they put me on Bezalip*

These examples are typical in that the rationale for choosing a particular number as a goal or trigger was seldom mentioned or queried. Often the source for the figure was (as in these examples) a generic ‘they’ rather than a specific doctor, and the value itself was recalled hesitantly, suggesting uncertainty:

*Claire: They put [Walter] on statins a few months ago and I think his cholesterol is what, 2.9?*

*Walter: 4.2 ... that is good or something, I don’t know what it all means, but 4.*

However, if the rationale for numbers was mysterious, they were tacitly accepted, even powerful, forces for eliciting action, as Henry’s mention of the ‘magic’ power of ‘5’ suggests:

*Henry: Every time it has been mentioned it has been below the magic figure, the 5.... 5.5, I can’t remember which it is, anyway whatever it is there is a threshold and it has been below the threshold*

That such numbers had an esoteric element did not mean patients were resistant to scientific evidence. Indeed, the roots of the numbers in “hard evidence” were an essential factor in their authority for some, as suggested by Don’s citation of “chemistry” in his exchange with his wife Mary:

*Don: I'm happy to take them, and just watch the hard evidence of the blood test every 6 months just to see what's happening, to that cholesterol, level....I would go very much by, you know, what ... those blood levels are telling me*

*Mary: Yeah, what your body's doing*

*Don: Exactly. Because I understand that ...er, there is a lot of chemistry there [laughs]...and it's ... what those results actually tell me, that lead me down a particular avenue .... of taking medication, or not.*

In a few extreme instances, the power of numbers as effective triggers to action persisted even though the construct being measured was not explicitly mentioned. In their account of Peter's hospital admission and treatment, for instance, Wendy and Peter carefully recall numbers, but it is opaque (at least to an outsider) to what 'the numbers' that triggered action referred:

*Wendy: You had, what was it? it was 0.02,*

*Peter: should be 0.02*

*Wendy: and yours was 8*

*Peter: 8.5*

*Wendy: and then Dr Jones said, when we get to 54 then we start to be a bit concerned*

In summary, quantitative information was widely cited, and recalled as effective in triggering action even where participants drew on limited knowledge of what the numbers were measuring or understanding of how threshold levels were chosen. So it seems unlikely that understanding, knowledge or recall about quantitative information is a *necessary* condition for making a health related decision, such as taking statins.

### ***Knowing but not using quantitative risk information***

In the few deviant cases where numerical risk information was mentioned in interviews, there was little evidence that it had any particular salience for decision making. Two excerpts from these atypical cases illustrate this. First, Bill recalls his risk of heart disease, but his subsequent comment suggests that what was significant for his decision was not this quantitative estimate, but the inference that this was 'normal', in that he was in the middle of a range and like other people his age:

*Bill: I think I'm on 11% chance of a heart issue in the next 5 years, or something – is that the one? is that the statistic which is about in the middle isn't it, I think, for men of my age? So – I think that's alright*



Second, Barbara also described her understanding of numerical risk estimates for heart disease as recalled from her GP's account. However, the hesitancy of both her recollection and decision suggest that these probabilistic figures were not a major influence on her decision to take statins. Again, her interview suggested that this did not reflect a lack of responsiveness to quantification in general, in that cholesterol readings, in contrast, were reported as being a deciding factor:

*Barbara: He said perhaps I ought to think about going on statins, and he showed me a display on his computer screen, of a hundred hearts, you know showing up percentages and telling me that if I took them for ten years I would reduce my risk by 4%, from 18 to 14%, or something like that.... I think those were the figures. So...er....I wasn't quite sure whether I wanted to – it didn't seem a huge...er, difference to me, really... the 4%.*

*But later: People talk about different numbers, er, and you don't really know what they mean, but, my cholesterol had gone up to 9 or something ... so I thought perhaps I ought to do something about it.*

### ***Talking about risk and prevention***

The rarity with which quantitative risk information appeared in the data cannot be explained by a lack of talk about or interest in reasons to take preventative medication. Indeed, such talk was very prevalent, prompted by the topic guide, but also raised spontaneously:

*Eric: Prevention is, the ideal, and everything else is, kind of backing up when things go wrong.*

*Simon: I think they just said ... something to take now, to help you for the future*

Explanations like Simon's, resting simply on being advised that action now would lead to benefit in future, were common. However, the *probability* of experiencing this benefit was rarely mentioned at all in the interview data, and never reported numerically. If future risks were mentioned, it was in generic, non-numeric, terms:

*Hazel: The doctor said to [my husband], you know, with blood pressure like this, untreated, you would have a major stroke or heart attack....which could well be fatal*

Further, when asked explicitly, patients rejected the idea that probabilistic quantification would be a useful aid:

*Don: It would have to be a very... personal thing, and a GP would have to say "Yes! aspirins would definitely help ... your particular case*

*Interviewer: Right. So “Out of 100 people exactly like you they’ll help 10” wouldn’t do it?*

*Don: No. Exactly, that’s right*

Two elements appear important here: a personalised message, and certainty about the future. Messages recalled as being personal and deterministic were reported as persuasive, as in Larry’s account:

*Larry: He pointed his finger at me and he said “If you want to live a normal life you take the tablets and you’ll live to be an old man .... Don’t take the tablets and who knows what will happen”. So, I have always taken my tablets*

Several other interviewees spoke of these elements as essential if advice is to trigger action:

*Geoff: I don’t particularly like ....being put on a regime of drugs which has been designed for an average person, or a person who falls into a very, very, very large category.*

*Liz: I think we would all be happy to take some things ... if we were absolutely convinced that it was necessary, but if it is just a possible thing then you have to think carefully about it*

Quantitative risk information was not, it seems, relevant to these two significant components of persuasive knowledge. It was, by definition, related to the population as a whole, not the individual, and it could not be deterministic.

## **Discussion**

### ***Summary***

Quantitative information about risk was not used in participants’ accounts of how they made the decision about statins. Our analysis suggests that this lack of salience does not reflect lack of knowledge, or aversion to quantitative data in general, as other numbers (such as cholesterol levels) were widely cited as decisive triggers for action. What did trigger decisions to take risk-reducing medication was unequivocal, personalised advice from a doctor.

### ***Strengths and limitations***

Key strengths of this study were that it included both those who did and those who did not decide to take statins, and that it drew on patients’ accounts generated in the settings in which decisions about medication use are likely to be made: the home, and between partners.

Couple interviews in particular captured the “everyday” talk which underpins people’s day-to-day decision-making. The study was limited to residents in East Anglia, a region with relatively

low heterogeneity with regard to ethnicity and socio-economic status; the generalisability of the conclusions to other contexts remains to be tested. That the interviews were conducted by a GP had potential disadvantages in that patients may have been either more reluctant or more anxious to demonstrate detailed understanding of 'medical' matters. We addressed this in the analysis by careful consideration of how the interviewer's expertise was attended to in responses, and by comparing the findings to those from other studies.

### ***Comparison with existing literature***

The contrast between the widespread citation of test results as important for decision making and the almost non-existent use of quantitative risk information in patients' accounts has not previously been highlighted in the literature. The scarcity of risk estimates in the data is surprising from a perspective grounded in the risk communication literature. However, this finding is perhaps less surprising in the light of a large body of other research which suggests that people's health decisions in general rely less on probabilistic future risk estimates, and more on advice that is regarded as applying to them personally (12-17), and given to them personally by a doctor (8, 18-22). Indeed, Gale et al (20) found that even people who had been taught how to interpret the results of risk calculations, and who demonstrably understood them, did not base decisions on them, preferring to ask their doctor what to do. This poses a challenge to the assumption implicit in much biomedical writing about risk communication (2) that people will heed and use numerical information once they understand it.

That participants do not mention risk estimates when talking about preventative medication, or do not use them as rationales for action, does not of course necessarily mean that these are not part of the useful backdrop of knowledge which patients draw on in making complex decisions about medication use. It is perhaps rare that health care decisions are made by patients acting simply as the 'rational choice agents' addressed by decision aids and described in game theory (23), and in practice a rather broader array of knowledge sources and values are brought into any particular decision. Davison's classic work on risk (24), for instance, identified a 'lay epidemiology' in which knowledge about coronary candidacy combined theoretical with experiential knowledge of known others who, for instance, lived to be 100 despite heavy smoking. Thus there was widespread implicit knowledge of the prevention paradox that interventions which benefit populations may harm individuals, and of the "irreducible uncertainty" of an individual's future, however definitely statisticians predict outcomes for a large population (25).

Others (26-28) have since examined the way that people use their practical knowledge alongside theoretical knowledge (29) from a variety of sources, to produce “rules of thumb” which guide their health decisions, for example about food choices or taking aspirin. In the process of combining different kinds of knowledge to produce these rules, theoretical knowledge about risk levels is undermined by tacit practical knowledge that the future is uncertain. As Rapley (30) suggests, decisions in practice are ‘distributed’, in that they are ongoing events involving multiple encounters and places.

Our data suggests that test results are widely heeded: they are facts about the present, and can be incorporated into an assessment of one’s state of health alongside facts like looking pale or feeling pain (31,32). It seems plausible that the salience of risk estimates is limited because they are facts about the future, inherently impersonal and uncertain. In building the body of practical knowledge which informs everyday decisions (33) such as taking long-term medication, facts about the future may not get a strong foothold, however well they are understood.

### ***Implications for research and practice***

Significant developments in research on cognitive understanding of risk communication have not been matched by our understanding of how such knowledge is used in practice by patients in making decisions about the use of medications such as statins. The finding that people seldom use quantitative risk information in making decisions about preventive interventions, if replicated elsewhere, raises significant questions for both research and practice: should communicating quantitative information remain a central component of clinicians’ endeavours to facilitate shared decision-making (34)? And should researchers working to make this communication more effective look at outcomes beyond ‘knowledge and understanding’?

If a painstaking discussion of numerical risk information has little or no effect on the patient’s decision, a cash-limited health service might decide to look for shortcuts to a patient-centred approach (35). One such shortcut might be found by following Elwyn’s (36) recommendation to offer a choice about participation in decision-making. For instance, saying “I would suggest you give statins a try, so as to make you less likely to have heart attacks in future – would you like me to show you the statistics about that?” may often elicit the reply “No thanks”, shortening the consultation without making any difference to its outcomes.

Such an approach is arguably more patient-centred than attempts to “engage ... patients in risk management discussions” (5), because it recognises a potential misunderstanding which

may undermine the project of risk communication in the context of prevention: to a clinician, preventative medication is synonymous with risk-reducing medication, but this small study suggests that patients may not consider “prevention” in quite the same way. At least in the context of preventive medication, some people may not base decisions on the probabilities of various possible outcomes, however effectively those probabilities are explained and however carefully weighted to reflect individual preferences and values

In summary, recommended approaches to communicating about risk are challenged by our finding that patients make minimal use of quantitative risk estimates when talking about preventive medication.

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## Summary

This paper provides a description of the role of numbers in accounts of medication decisions. It presents two main findings, one positive and one negative, and explores the contrast between these two. The negative finding is that participants do not use quantitative risk information in accounting for their medication decisions. An explanation for this finding widely implicit in the literature about ‘risk communication’ is that people do not use their risk estimates because they do not understand what these numbers mean. But this explanation is challenged by the positive finding presented here: participants do use quantitative information such as test results in their accounts of medication decisions, despite not understanding what those numbers mean. In the data cited in the paper, people frame the number that describes their cholesterol, for instance, as a goal or trigger for action; in one data excerpt a couple explain in some detail how a numerical test result determined the best course of action, without ever mentioning what entity was being measured. In this extreme example, the numbers themselves are reified, but more commonly it is the entity being measured (cholesterol or blood pressure, for example) that appears in participants’ accounts as an agentic character in its own right. The numbers used to describe characters such as cholesterol or blood pressure enable comparison with ‘*magic*’ threshold levels, and these comparisons are used to explain medication decisions. The threshold is often left unspecified, and where it is specified it is explained only as being ‘*where they want it to be*’, as one participant said when talking about his cholesterol.

For students and practitioners of shared decision making and risk communication, the paper’s main intended audience, the key point here is that the lack of an agentic role for quantitative risk estimates in accounts of medication decisions raises questions about the usefulness of providing patients with information about such estimates. The paper also points to a further line of enquiry: the finding that people do use test results, despite indicating (sometimes explicitly) that they do not know what these numbers mean, suggests a need to look beyond ‘lack of understanding’ for a way to explain why information about the likelihood of future illness is not used. The explanation offered here is that whether or not health information gets used depends on the kind of problem the information is about; some kinds of problem are presented as needing action while

others are not. This explanation points to the central question addressed in the next chapter: what determines whether or not a problem needs action?

Constructing a typology of problems to answer this question, a ‘common sense’ starting point is the distinction between illnesses (whose status as ‘*episode[s]*.... *where you need medication*’ is generally uncontested) and invisible, intangible problems such as high levels of cholesterol or of risk. The findings presented in the paper above highlight a distinction that is harder to characterise and explain: the distinction between cholesterol, which is accorded ‘*condition*’ status in these data and thus necessitates treatment, and risk, which is not framed here as a trigger for action. The paper in the next chapter complicates the apparently obvious distinction between illnesses and conditions that people know they have despite feeling well; it offers an account that helps to explain the distinction between treating cholesterol and treating risk, and to problematise the way ‘prevention’ is constituted in these data.

## **Chapter 4: Constructing ‘a condition needing treatment’ while feeling well**

*Liz: ‘We would all be happy to take some things ... if we were absolutely convinced that it was necessary, but if it is just a possible thing then you have to think carefully about it.’*

### **Introduction**

The previous chapter describes the way test results are reified and used in accounts of medication decisions, and contrasts this with the lack of use of risk information in such accounts. This chapter builds on that description, taking the contrast between risk information and test results as the starting point for an exploration of the process of reification, and offering a detailed picture of the ways in which people become ‘*convinced that [statins are] necessary*’. This empirically grounded picture is used in the following paper to foreground the salience of time as a dimension of the knowledge participants reference in accounts of their decisions and practices, and to problematise the assumption that framings centred on risk and uncertainty are helpful for understanding decisions about preventive medication.

### **Paper 3: Current conditions or future risks: certainty and uncertainty in decisions about statins**

Polak, L. (2016). Current conditions or future risks: certainty and uncertainty in decisions about statins. *Health, Risk & Society*, 18(3-4), 153-167. doi: 10.1080/13698575.2016.1183767

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## **Abstract**

Preventive medications such as statins are recommended to an increasingly large number of people. To those who make these recommendations, prevention is synonymous with risk reduction; the clinical task of helping people decide about preventive medication is therefore widely framed as one of risk communication. In this article I explore the role of risk and uncertainty in accounts of medication decisions, drawing on qualitative data from interviews carried out between 2011 and 2013 in the east of England with people who had been offered statins. I found that very few participants mentioned risk or likelihood, or described weighing benefits against harms, the process central to the risk communication project. Instead, those who had decided to take statins described their certainty that statins were needed to treat current problems. This certainty was informed by knowledge about the present or the past; information about possible future harms was presented solely as contributing to concern about current problems. In contrast, those who had decided not to take statins explained their decisions in terms of the inherent uncertainty of information about the future, presenting this uncertainty as a reason to decline medication. This asymmetry between explanations for accepting and for declining statins is rooted in differences between the ways past, present and future information are handled. These findings challenge the assumption that decisions about statins are construed as decisions about risk by those offered them and raise questions about the usefulness of using risk and uncertainty as key concepts for theoretical accounts of what is going on when people consider taking preventive medication.

## **Keywords**

Risk, uncertainty, risk communication, prevention, time, decision-making, statins

## **Introduction**

In this article I explore the role of risk and uncertainty in decisions about preventive medication, using data about deciding whether to take statins to problematise two related assumptions: that such decisions constitute attempts to deal with the inherent uncertainty of the future and that prevention is widely equated with risk reduction. This exploration is underpinned by an account of the way the concepts of prevention and treatment articulate to inform decisions about preventive medication.

## **Risk and prevention**

Prevention is a central feature of most health policy agendas; for instance, a recent document setting out objectives for the NHS in England (Stevens, 2014) devotes a chapter to it. While much of Stevens' chapter considers population-based interventions, continuing enthusiasm for individually-targeted approaches is illustrated by the ongoing NHS Health Checks programme (NHS, 2015), which screens individuals so as to 'predict and prevent' cardiovascular disease, and by the latest UK guideline's related recommendation (NICE, 2014) to lower the risk threshold at which people should be encouraged to take statins. The effect of these individual-focused approaches is that increasing numbers of people are offered preventive medication. This increase in numbers is starting to be amplified by a rapid expansion of the potential for geneticists to identify new groups of healthy people as being 'at risk' of future disease (Levy-Lahad, Lahad, & King, 2015), closely followed by the advent of new individually-targeted preventive options for people in these 'high risk' groups, such as tamoxifen for women with a high risk of developing breast cancer (NICE, 2013). Like most such medications, statins produce no discernible health benefits for the individual taking them – even if that individual never has a heart attack, we cannot know whether this was thanks to the statin, only that it made a heart attack less likely. This uncertainty presents challenges for clinicians who are enjoined to encourage people to take statins and other preventive medication. It also makes prevention decisions an interesting object of study, a context which seems 'an extreme case, a setting in which we could assume that there are overriding incentives for talking about and with risk' (Green, 2009).

From a biomedical perspective, prevention is synonymous with risk-reduction, so the burgeoning of preventive medicine has strengthened the role of 'risk communication' as a cornerstone of the clinical task of engaging patients in decisions about their medical care. Discussing a study of this task in the context of genetic risks, Prior et al (2002) characterise its central challenge as 'melding epidemiological data with data about an individual' in order to give that individual their own risk prediction. Ways of communicating risk information are the topic of a growing body of research (Trevena, Davey, Barratt, Butow, & Caldwell, 2006) which supports the widely-accepted recommendation that this information should be communicated quantitatively (Trevena, 2014); the patient is to be given an estimate of their risk of future benefits and harms, derived by combining population-based evidence with biomedical information about their own body (such as their weight, cholesterol level and medical history), and also incorporating information about their ideas and concerns and the value they attach to each element of the decision. Algorithms have been developed to help a patient collate this information about themselves and their values, and then work out the best decision for them, considering relevant population-based information; these decision aids are themselves the subject of a large literature (Stacey & al, 2014). Here, as in the literature on risk communication in general, a key assumption remains tacit: that people use information about risk in making health decisions.

Several studies raise questions about the extent to which people do use risk information; Gale et al (2011), for instance, found that even after being given relevant information and carefully shown how to use it to decide about statins, people preferred to ask their doctor what to do. The importance patients place on the quality of interaction with the doctor supporting treatment decisions is highlighted by Entwistle, Prior, Skea and Francis (2008). This sheds light on the finding by Bhavnani and Fisher (2010) that while their participants welcomed decision aids as a source of information, they were 'seen as poor substitutes for people' when it came to making decisions. These studies examine decisions taken within the context of clinical encounters, with a doctor-patient relationship placed centre stage; less is known about decision-making outside this context. Rapley (2008) suggests that his account of decisions as 'distributed' (spread across a variety of places and times, and involving

encounters with a variety of actors) indicates ‘an alternative trajectory of ...researching healthcare decision making’. Decisions about statins are very likely to be distributed in this way because, like most preventive medication, they need to be taken regularly at home over long periods in order to achieve the risk reduction which policy-makers are aiming for. It is therefore worth looking at how decisions are taken outside the clinical encounter, as I do in this article.

Medication decisions are widely studied beyond the biomedical literature, which has a strong focus on communicating information about risk and helping people to use it rationally. Zinn (2008) highlights the value-laden dichotomies inherent in this biomedical approach, classifying the knowledge used in the process as either theoretical or practical, and the process of decision-making as either rational or irrational. That these classifications are value-laden is illustrated by a comment in an article (Elwyn & Miron-Shatz, 2010) which seeks to define a good decision: ‘choices made in the absence of any knowledge are mere guesses’. This comment suggests that a patient might have no knowledge at all if not provided with implicitly-objective medical information, evoking Charles, Gafni and Whelan’s (1999) warning against considering the patient as ‘an empty glass [to be] filled up with new knowledge’ in the context of shared decision-making. The reference to ‘mere guesses’ highlights the low status Elwyn and Miron-Schatz (2010) accord to irrational (or in Zinn’s terms, intuitive or in-between) decisions; this judgement is critiqued by Heyman, Alaszewski and Brown (2013), illustrating Zinn’s (2009) account of a move amongst sociologists to reject the narrow focus on rational choice which he says remains dominant in the biomedical community.

Nonetheless, both biomedical students of risk communication and those who criticise their approach share a central assumption: that decisions about preventive medication constitute attempts to deal with the inherent uncertainty of the future; Zinn (2008), for example, writes about ‘uncertainty management’ as a key objective of decision-making. This casting of uncertainty as a central character, either in descriptive accounts of decision-making or in more theoretical analyses, is problematised here, drawing on an empirically-grounded description of the way participants explain how they made up their minds whether or not to take statins. In this article I examine the



concepts of prevention and treatment which inform these explanations, asking whether people use information about possible future problems to account for decisions about preventive medication, and exploring the way uncertainty is handled in making these decisions.

## **Methods**

The data I draw on in this article come from a study that set out to examine distributed decision-making about statins, rather than on one-off decisions made within medical consultations. Statins were chosen as a particularly unequivocal example of a medication prescribed purely for prevention. To focus on how people make decisions over time within their everyday lives, I interviewed individuals recruited from non-clinical settings, using invitations to community groups such as lunch clubs and an exercise class, and snowballing from initial participants. All participants were interviewed in community settings, most in their homes.

I conducted face-to-face interviews that were audio-recorded and transcribed verbatim, with 34 people aged between 53 and 87 in East Anglia between 2011 and 2013. These interviews were semi-structured, using a brief topic guide which included questions on participants' health and how they looked after it; where their knowledge about health came from; and their decisions about and use of medication in general and statins in particular. I obtained ethical approval (reference 6142) from the London School of Hygiene and Tropical Medicine ethics committee before data collection began. All names in this article are pseudonyms, and I have removed any information which could identify a participant.

All participants had been offered statins, and over half were currently taking them. About half had suffered a heart problem requiring urgent hospital admission; some did not specify the precise diagnosis while others expressed uncertainty about it, but all mentioned heart attack, angina or blocked arteries. For simplicity, everyone in this group is referred to here as having had a heart attack.

I interviewed 22 participants with their partner and 12 individually; couple interviews can offer advantages over individual interviewing as a way of studying everyday practices and the often-tacit discourses that inform them, because interactions

between the two participants in a dyadic interview provide additional analytic purchase (Polak & Green, 2015a).

My analysis was informed by regular discussion with colleagues, using elements of a grounded theory approach (Strauss, 1987) to generate and test hypotheses concerning the kinds of knowledge used in accounting for medication decisions and the processes involved in reaching them. Our analytic strategy was to focus on what people did and knew, rather than on what they did not; this emphasis led for instance to an early shift of focus away from the absence of uncertainty to the constituents of certainty in the data. Such shifts were facilitated by an iterative approach that enabled unexpected findings to emerge throughout the research process and prompt new lines of enquiry.

### **Findings**

The central question I shall address in this section is whether study participants accounted for their decisions about preventive medication in terms of preventing future problems (in line with the logic of risk management) or in terms of treating current problems. This leads into a broader question about the way uncertainty is handled in making these decisions. A starting point for these enquiries is to explore the way the concept of 'prevention' articulates with the concept of 'treatment' in participants' accounts.

Many participants echoed the widespread trope that prevention is a good thing, a sensible objective, as several common sayings show: 'Better safe than sorry'; 'Prevention is better than cure'. Participants mentioned prevention approvingly as an objective, implying that it is clearly distinct from treatment, which is what you need 'when things go wrong'. As Eric, who decided not to take statins when they were recommended for increased risk, noted: 'Prevention is, the ideal, and everything else is, kind of backing up when things go wrong'.

One popular saying presents prevention as a practical measure: 'a stitch in time saves nine' conveys the idea that preventive actions are taken now in order to stop something bad happening in future. This fits with what Simon said about his statins: 'I think they just said ... something to take now, to help you for the future'; this suggests a tidy linear model of the relationship between prevention and time, but elsewhere in

the data this simple model seems to fit less well, and instead the picture which emerges is of 'prevention' as a slippery concept, hard to separate from 'treatment'. Hazel's account, recalling how her husband Ted came to start taking pills 'for his blood pressure', illustrates this:

The doctor said to him, you know, with blood pressure like this, untreated....within 18 months to 2 years you would either have either had a major stroke or heart attack...which could well be fatal.

This illustrates the tangled way in which test results and doctors' advice articulate not only with each other but also with future problems: it is primarily a story about the need to take tablets because of a definite current problem, and only secondarily about preventing a future problem. For Hazel, Ted's blood pressure was a feature of his current state of health, implicitly reified and assessed as being a problem by the doctor's reference to 'treating' it, as well as by common knowledge that high blood pressure is bad for you. The doctor's warnings of future disasters, made more compelling by the precise time-framing, served to reinforce this common knowledge. The key elements of Hazel's story are seen in almost all accounts given by participants who had decided to take statins: the story's central character is a current problem, rendered salient by information about possible future problems. While these elements are shared by accounts both from people who had and who had not had heart attacks, two additional salient elements, information about past and present feelings, feature only in the stories after heart attacks. So it is helpful to consider the two groups of accounts separately, while bearing in mind their shared features and in particular the way these features are situated in time.

### ***Reifying test results as current problems***

Almost everyone taking statins without having had a heart attack presented the medication as necessary treatment for 'cholesterol', a term widely used as shorthand for 'raised cholesterol level'. This shorthand does not elide the evaluation suggested by 'raised', however; cholesterol is widely reified not simply as a neutral entity but as a problem. The negative evaluation is often tacit, as the next excerpt illustrates; like Ted's 'blood pressure' in his wife's story above, 'cholesterol' is clearly a bad thing to

have, something doctors prescribe treatment for, as Kathy described: 'They decided that I needed, I had cholesterol so that's what I got put on'.

Kathy's is typical of most accounts in implicitly presenting cholesterol as a current problem, both reified and evaluated in the present. A few participants, however, separated reification from evaluation, situating the two differently with regard to time. For example, having presented his cholesterol level as a current feature of his body, Ed went on to talk about a possible future feature of his body to explain why cholesterol is a bad thing: 'They said "watch the build-up of cholesterol, because it could narrow your arteries and so on"'. Ed was unusual in volunteering this future-centred explanation without being prompted by a question from the interviewer about why cholesterol matters, but such prompting did lead several others to offer similar explanations, sometimes going beyond narrowed arteries to illnesses, as Debbie does in the next excerpt. Her husband, Keith, had had a heart attack, and Debbie explained:

We know that if our cholesterol is high ... then you are going to get furring of arteries and then you are going to get a problem such as Keith has got.

It is interesting that explanations like these were seldom given until asked for; it seemed to go without saying that cholesterol was bad and needed treating. Thus, although knowledge linking cholesterol with heart disease was quite often made explicit by a direct request from the interviewer, it appeared to be taken for granted by participants, elided from accounts which framed cholesterol as an object of concern in its own right, a definite current problem, rather than as a currently-harmless object which might possibly lead to problems in future. This reification of cholesterol was sometimes strengthened by detailed stories like Don's here about 'the hard evidence of the blood test':

I saw the figure on the screen ...I think it was only about, 3.6 or something... I'm happy to take them [statins], and just watch the hard evidence of the blood test every six months just to see what's happening, to that cholesterol level.

Don's use of numbers to describe his cholesterol might suggest that it was precision which made the blood test result into 'hard evidence' and hence into a trigger for

action; additionally, seeing ‘the figure on the screen’ might have increased its cogency. But neither visual presentation nor numerical precision necessarily make information cogent, as illustrated by the way Barbara explained how she initially declined statins when the advice to take them was based on risk information, but later decided to take them because of her cholesterol level:

He showed me a display on his computer screen.... telling me that if I took them for ten years I would reduce my risk by 4 per cent, from 18 to 14 per cent, or something like that.... I think those were the figures. So...er....I wasn't quite sure whether I wanted to – it didn't seem a huge...er, difference to me, really... the 4%.

[*But later*] My cholesterol had gone up to 9 or something ... so I thought perhaps I ought to do something about it.

It seems that, unlike cholesterol, risk of future harm is not reified here; even when precisely specified, and communicated visually, it does not become a current problem and so does not act as a trigger for taking pills.

***Past illness: taking medication to control ongoing problems***

‘Cholesterol’ was presented as a current problem legitimising decisions to take statins. In addition, participants who had previously suffered heart attacks talked about a different kind of current problem when explaining why they took statins: ‘heart problems’. All these participants said they felt well at present, but they often indicated a perception that they still had something wrong with their heart now, a current problem for which their statins were necessary. Their knowledge of this problem was based not on information about the present (they did not feel ill) but on information about the past. The next excerpt enables a helpful comparison with another chronic health problem, arthritis; Fiona’s account of the way she knew she needed her arthritis pills exemplifies the way knowledge about present, past and future articulate with each other:

With the rheumatoid pills I know that if I don't take them I'll be in a wheelchair. There's no doubt whatsoever in my mind about that, because when I first had the rheumatoid arthritis I just shrivelled up like a prune didn't I?

Fiona knew she had arthritis in the present, waiting to make her ill again in future if she stopped her medication. Her knowledge was based at least partly on vivid embodied memories of illness in the past.

Participants talked in a similar way about their heart attacks, about which many told dramatic stories. Like Fiona, they used this information about past illness to explain that they would not want to try stopping the medication, because it was keeping them well. Chris, who started statins after his heart attack, made “drugs’ ” vital role explicit:

It’s drugs that keep us alive now...my parents, they both died in their 70s... they had heart problems, but of course they didn’t have the medicine.

Elsewhere in the interview Chris spoke of himself, too, as ‘[having] heart problems’, using the present tense, although he felt well now that he had recovered from his heart attack. The drugs ‘keep [him] alive’ by controlling these problems, which are implicitly still present just like Fiona’s arthritis; rather than a story about drugs preventing him from having further heart problems in future, this is about drugs treating a condition he has now, in the present.

Very few participants did talk explicitly about avoiding future problems as a reason to take medication. Jim was one of these, in his story about his father’s stroke:

When he [father] had the stroke he was paralysed ... it was horrendous seeing a really fit man,... so that was what happened to my father, so anything they give me, because I didn’t want to die like that ... anything they can give me to stop anything like that I didn’t mind.

Jim’s memories of his father’s illness seemed as vivid as Fiona’s of her own – he used the word ‘horrendous’ twice in the passage from which this is an excerpt – and so it seems plausible that these memories made him see himself as vulnerable in the present, just as Fiona’s directly-embodied memories did; it was this current vulnerability which both of them used to account for their decision to take pills to prevent future harm. In the following excerpt, talking with her husband Walter, Claire was one of the few others to say that the point of taking statins since her heart attack was to obtain benefit in future:

*Walter:* I think what those pills do is [he pauses] ...they are doing the job aren't they, you know, they must be doing the job

*Claire:* No, it is like if you take a paracetamol you take it for a headache and you know that you will eventually get a bit of an effect within the hour, but the pills I am taking I don't really, you know, if I stopped taking my pills now I wouldn't feel any different either would I, because they are not immediate effect type of pills.

Walter's hesitation here points to the difficulty of knowing (or at least, of explaining) 'what those pills do'. Claire's 'No' seems to pick up on his difficulty, rather than contradicting him, but, like him, she elided any definition of what the pills do, ending up just saying that they did it in the future, not now.

Others who had had heart attacks spoke as though, unlike Claire, they found it easy to assess the pills' effectiveness, but they gave no indication of considering any future effects. Neil stated that; 'I am feeling better, to me it's obviously doing some good', while Simon commented: 'So far it's working very well... I've got no complaints'. These statements, like Walter's 'they must be doing the job', convey a certainty which is impossible to found upon knowledge of future effects, and indeed Neil and Simon specified that their assessments rested upon the way they felt now and had felt 'so far' – upon embodied knowledge about the past and the present. There is no echo here of Claire's awareness that these 'are not immediate effect type of pills'; 'the job' Walter mentioned was to treat a current problem, just like Fiona's pills treat her arthritis, and like her, he was certain about the need to take the pills.

### ***Certainty, uncertainty and choice***

Participants who took statins almost all said they certainly needed their medication, rather than having chosen to take it; the concepts of 'need' and 'choice' were often implicitly presented as mutually exclusive. Indeed, with few exceptions, the only people who indicated uncertainty about this need were those not taking statins. In the accounts of the people who had decided against statins, uncertainty was sometimes explicitly cast as a reason to decline medication, as Liz explained:

I think we would all be happy to take some things ... if we were absolutely convinced that it was necessary, but if it is just a possible thing then you have to think carefully about it.

Liz's account highlights two lines of enquiry, one into the kinds of knowledge that make people 'absolutely convinced' they need pills when they feel well, the other into the process through which conviction is achieved – what constitutes 'think[ing] carefully' and differentiates it from feeling 'happy to take ...things'? Both are illustrated by the following excerpt. Geoff was answering a question about the difference between statins (which he had previously said were recommended to prevent a heart attack) and medication for his longstanding asthma:

Preventative medicine for asthma ... well, you've had asthma, that doesn't even really need to be talked about, but, this [statins] needs a little bit more thought.... If I had a crystal ball and you said 'Well I have got the machine here which can show you a video of the day where [sic] you have your heart attack', of course it would – I'm sure.... I'd see it much more the way I see...the asthma stuff .

This illustrates that questions about the kinds of information people use in decision-making cannot be neatly disentangled from questions about the process by which they make up their mind; the two are inextricably linked because both centre on certainty and uncertainty. What Geoff's account highlights is not a difference in badness or likelihood between asthma and a heart attack, but a difference in certainty. The imagined video served to erase the difference in certainty between events in the future and events in the present or the past, moving the heart attack from the future into the present, as Geoff's use of the present tense ('you have your heart attack') shows. This present-simulating effect is underlined by the way he talked about a visible picture, with the particular cogency of visual communication emphasised by his 'where you have your heart attack', the 'where' suggesting an event situated in a specific place and time. Thus the video (if it had existed) would have been a good substitute for his highly-salient embodied memories of asthma. In reality, with no crystal ball, the difference was that Geoff could not get the 'utter certainty' about needing statins that



his past experience had given him about needing his asthma medication – as the earlier examples about people with arthritis or heart problems show, experiential knowledge about the past is accepted as a valid source of knowledge about the present, and therefore as an adequate basis for decisions, whereas information about the future is not. So, whereas the need to take his asthma preventers ‘goes without saying’ for Geoff, statins ‘need a little bit more thought’. This perhaps encapsulates the difference between an intuitive decision and a rational one, and Geoff’s account indicates that intuitive decisions can be informed only by practical, embodied knowledge.

Later, Geoff implied that impersonal, population-based information was inherently lacking in cogency:

I don’t particularly like ... being put on a regime of drugs which has been designed for an average person, or a person who falls into a very very large category.

Don made a similar point in his response to a question about his decision to decline aspirin, which he had been offered to reduce his risk of future heart problems:

*Don:* It would have to be a very... personal thing, and a GP would have to say ‘Yes! aspirins would definitely help ... your particular case.’

*Interviewer:* Right. So ‘Out of 100 people exactly like you they’ll help 10’ wouldn’t do it?

*Don:* No. Exactly, that’s right.

Don’s account again indicates the entanglement between two factors which would lead him to decide to take preventive medication: the right kind of information and the right kind of deciding process; what he said would be persuasive is the combination of definite personal information and a GP saying ‘Yes!’. The cogency of doctors’ advice is evidenced elsewhere in the data, mostly in explanations given by people who took statins, and particularly those who had had heart attacks, who often talked of statins as part of the medical treatment which rescued them when they suffered their frightening illness. David’s account exemplifies this:

I was given a new lease, wasn't I? And they found things, so I've got to do what I'm told....I mean, if the doctor says I need then that's it.

David was making an explicit causal link from being rescued after his heart attack to his willingness to accept medication 'if the doctor says I need', although the way his explanation also rested on their having 'found things' (implying that these 'things' were current ongoing problems) indicates that here again the decision was based both on knowledge about current health problems and on unequivocal medical advice.

In the next account, where Simon and his partner Gill talked together about his heart attack, '[doing] what I'm told' was not even problematised:

*Simon:* They gave me a whole load of pills...being in hospital –

*Gill:* I think you had no choice. It was, in the package.

A salient feature of stories told by people who were taking statins was that they had 'no choice' about taking medication. This was particularly explicit in the stories of those who had had heart attacks, but even those who said they took statins to treat their cholesterol surprisingly seldom talked about choosing to take them; in general, people said they took statins because they definitely needed them. The option-weighting process, central to accounts of rational decision-making, was conspicuous by its absence from this data. Fiona gave the only explicit example of weighing up pros and cons, describing two separate concerns that led her to throw her prescription for statins straight into the bin; the first was the increased cost of travel insurance:

It seems funny when you're sort of, weighing your life against an airline ticket, you know, the insurance for a holiday, but there again life isn't worth living if you can't enjoy it.

A second concern, about side effects, was echoed by several others who were not taking statins but by very few who were. Fiona's account of the likelihood of unpleasant side effects demonstrates awareness of the inherent difficulty of using risk estimates to inform individual decisions:

I'm very susceptible to all sorts of, things when I take pills....They were all put down as symptoms that don't occur often, you know, very rare ones, but... well, I got them.

There were surprisingly few other instances where someone indicated considering likelihood, and (as we have noted elsewhere (Polak and Green 2015b)) references to quantitative risk information were rare. Debbie's use of a risk estimate, in the next excerpt, was clearly rhetorical, emphasising the way a particularly strong concern dominated her decision-making to the extent that it sounded more like an intuitive process than a rational weighing of benefits against risks:

I got them home, looked at the contraindications, sometimes permanent loss of vision. Now I know this is one in a million but I don't want to be that one in a million, you know, so they went on the shelf [not to be taken].

Fiona summed up the way people decide against statins, contrasting them with her clear need to take her arthritis pills: 'With statins ... it's a preventive thing and you haven't seen any..... need to take them'. This illustrates that people take medication when they 'see' a need to do so, rather than because they follow a rational process leading to the conclusion that they should take them. What makes people see a need to take medication is certain knowledge about the present, and information about possible futures is used only to support the characterisation of features of the present as problems. In this data, talk about choice and uncertainty was present only in accounts of deciding not to take statins.

## **Discussion**

Information about the future was not used to account for taking statins by participants in this study; only those who had decided against statins talked about the future's inherent uncertainty. Instead, people who were taking statins referenced information about the past and the present – practical, embodied knowledge of how a heart attack felt, and theoretical, discursive knowledge about their cholesterol. These two apparently-different kinds of knowledge were handled in a similar way, a functional similarity described in Blaxter's (2009) auto-ethnographic account of an illness: she found her test results contributed to her perception of her body alongside sensory

information, a phenomenon she identifies as distributed embodiment. The incorporation of test results into the collection of knowledge about one's body which informs health decisions is also central to Lupton's (2012) account of the way people use numerical information about their body produced by their mobile health device, information which Lupton describes as constituting a 'data double'. Handling test results in this way can be seen as expanding the spatialisation of health and illness beyond 'the solid visible body', as Foucault (1973 p3) describes doctors doing, and demonstrates that this particular expansion is not visible solely to the medical gaze through which it originated; it is not only doctors who include test results alongside directly-embodied information in their assessment of the body's state of health, as the findings presented here show.

However, this apparent sharing of gaze does not necessarily apply to other dimensions along which spatialisation gets expanded by doctors in the move from offering treatment to sick individuals to offering preventive interventions (such as statins) to whole populations. This move, central to Armstrong's accounts (1983, 1995) of the evolution of Surveillance Medicine, involves two expansions of spatialisation that were visibly problematic for participants in this study: the extension of gaze from an individual to a population, and expansion along a time dimension.

Several participants explicitly rejected population-based information as a trigger for action, speaking of preferring treatment which 'would definitely help ... your particular case', and of disliking being treated as 'an average person'. This rejection echoes Blaxter's (2009) account: in contrast to her ownership of the test results themselves, she describes the sense of alienation which arose when her test results and bodily features were translated by doctors into indicators of future risk, used within standardised algorithms to determine the best treatment for her. She discusses the way this protocol-driven approach, informed by population-based evidence and 'welcomed... [by] medicine... as offering certainty', may 'foster the "disappearance" of the patient'. Alaszewski and Brown (2015 p35) note the inherent uncertainty of probabilistic information in relation to individual patients, rendering it of limited usefulness to them in 'rework[ing] futures'. Polak and Green (2015b) report that, unlike numerical test results, quantitative risk estimates were seldom used in deciding

about statins, a finding they ascribe both to the impersonal character of probabilistic information and to its future dimension.

Time is a dimension central to Armstrong's account of expanded spatialisation; he describes doctors using surveillance to analyse 'a four-dimensional space in which a temporal axis is joined to the living density of corporal volume' (1995). However, time is not a novel dimension produced uniquely by the move away from an individual-focused to a population-focused medical gaze, nor is it visible only through that medical gaze; self-assessments of an individual's state of health, too, involve a time dimension. Both Blaxter (2009) and Lupton (2012) describe the way past test results serve as a comparator for assessing present results; Lupton's virtual doppelganger interacts with its user through feeding back information which encourages her 'to act in certain ways' which in turn affect her test results, while Blaxter found herself hoping to 'perform' better in lung function tests than she had done previously. Participants in this study, too, worked with a four-dimensional picture of themselves which incorporated embodied memories and past test results, using this picture to inform decisions about statins.

Where preventive medicine does produce an expansion is along the future portion of the temporal axis, a change enabled by gathering information about populations. This new focus on future illness is seen in the evolution and rapid growth of a new group of entities, 'risk factors': attributes like cholesterol which are harmless in the present but make future harm more likely. This study suggests that these attributes lose their future dimension in the process of reification, coming to be presented as current problems. Reification thus involves a black box which makes test results cogent; where the box is opened to display population-based information about the future, that cogency is lost. For example, estimates of cardiovascular risk do not constitute a stand-alone reason to take medication in this data; where information about the future is presented as a factor in deciding to take medication, it appears in a supporting role, contributing to knowledge about the present in a way which makes the two difficult to disentangle. In contrast, the inherent uncertainty of information about the future is frequently presented as a cogent reason to decide not to take medication.

The way these participants talked about their cholesterol or their heart problems as current problems is similar to the way people talked about having an aneurysm found by screening in a study by Hansson, Brodersen, Reventlow and Pettersson (2012): all their participants presented the aneurysm as a current problem, one which many described as extremely serious, even 'a life sentence', despite the fact that a majority of them would never come to any harm from it and it was not making them feel unwell at present. Reventlow, Overgaard, Hvas and Malterud's (2008) study of perceptions of osteoporosis highlights this same reification, describing a relationship with information very like the distributed embodiment Blaxter (2009) reports. Reventlow et al's account can be seen as illustrating the inextricable entanglement of current problem and future risk highlighted in this paper: like cholesterol, osteoporosis is perceived as a problem definitely present in the body now which engenders anxiety about possible future problems.

In another study concerning osteoporosis, Salter et al (2011) explore 'the meaning of risk status as an illness experience' and cite the growing literature about potential harm this liminal status may cause. Their participants had received a letter saying a screening result showed they were at risk, so it is unsurprising that the data included talk about risk of future fractures; what is interesting is that many of the data excerpts presented also appear to show people reifying 'thinning bones' as a definite current problem, just as participants in the study presented here reify cholesterol as an object of concern in its own right. In contrast to Salter et al's account, and others focusing on what Aronowitz (2009) calls 'the convergence of risk and disease', concern about being 'at risk' of future problems was very seldom visible in this study. Even participants who had had heart attacks talked not about the risk of another attack in future but about knowing there was something wrong with their heart now; where references to future risks did appear (usually made explicit in response to direct questions) they functioned only indirectly as reasons to take statins, strengthening the characterisation of past illness or reified test results as 'problems'.

From a biomedical perspective, decisions about preventive medication are obviously decisions about risk. Scott, Prior, Wood and Gray (2005) state that for people identified in a genetic clinic as at increased risk of cancer, 'it is risk itself that

constitutes the *raison d'être* of medical intervention'; yet while this is clearly true for the clinicians recommending the intervention, it was not the primary reason participants used here in explaining why they took statins - it was elided from most explanations. Green (2009) highlights the limitations of a risk-based framing, both as a way of describing and a way of analysing what is going on, but most moves to broaden it are confined to a shift of focus from risk to uncertainty (Zinn, 2009), keeping the future as a central character in the story. Brown, Heyman and Alaszewski (2013) illustrate this focus on uncertainty and the future, discussing the way 'decisions amidst uncertainty' are informed by evaluations and experiences of 'future-time'. This framing has some explanatory power concerning the findings presented here about people who were not taking statins: uncertainty reduces the value of information about the future, requiring careful deliberation and thus rendering the information an inadequate reason to take medication; in this data, 'you have to think carefully about it' generally means you decide not to take it. For those who were taking statins, however, and hence for the data as a whole, a different framing supports a stronger story about what was going on: people took medication because they were certain they needed it. In the case of statins, this certainty is incompatible with any rational assessment of statins' benefits; an individual cannot know for certain whether they will prevent harm in the future. These findings suggest that people decide about statins by building certainty to support an intuitive decision which is presented as '[having] no choice'.

## **Conclusion**

In this article I have argued that risk information has far less salience to decisions about preventive medication than a biomedical perspective would suggest, and that the way people use information in making up their minds about medication has little in common with the rational choice model upon which most risk communication approaches are based. For the clinicians who actually do risk communication, it will be useful to realise that there may be a mismatch between their perspective and their patient's concerning the aim of preventive medication: the patient is unlikely to equate prevention with risk reduction, and is likely to accept medication such as statins primarily in order to treat a definite current problem. At a more analytical level,

the findings I present support concerns that the lens of future risk may unhelpfully constrain exploration and theoretical accounts of health decision-making, and suggest that replacing it with an uncertainty-centred framing may not go far enough to avoid these constraints; a bigger move is proposed, focusing on the kinds of knowledge used to constitute necessity and certainty, and on the way past, present and future information are used in building this knowledge.

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## **Discussion**

This paper problematises assumptions central to two bodies of research and debate. At a practical, biomedical level, the enterprise of ‘risk communication’ rests on the assumption that, like doctors, patients frame the potential benefit of statins as risk reduction. At a more theoretical level, the paper casts doubt on the assumption that uncertainty, likelihood and risk are useful concepts for understanding how people decide about preventive medicine. This doubt extends to the usefulness of a risk- or uncertainty-centred framing for understanding health decision making in general, because preventive medication seems ideally cast as ‘an extreme case, a setting in which we could assume that there are overriding incentives for talking about and with risk’ [Green, 2009] – in what context would patients talk about risk, if not in this one?

In these data, uncertainty about whether or not statins will be of benefit is indicated only by participants who are not taking statins; in these participants’ accounts, uncertainty is sometimes explicitly presented as a reason for deciding not to take statins. Participants who say they are currently taking statins present them as certainly necessary. This highlights the question, what are they needed for? By offering some answers to this question, the thesis contributes to the sociologies of diagnosis and of disease. The sociology of diagnosis underpins many of the arguments developed in this thesis; in terms of Jutel and Nettleton’s [2011] helpful distinction between diagnosis as category and diagnosis as process, the current chapter presents findings about the categories participants use and the role these diagnoses as categories play in accounts of medication decisions. (The process by which diagnoses are established is explored later in the thesis, within an account of knowledge construction in Chapter 6.) For the sociology of disease, the indissoluble reciprocal connection that I identify between needing medication and having a condition complicates Timmermans and Haas’ [2008] aspiration to engage with ‘the biology of disease’ and address questions about ‘whether a disease is ‘real’ or not’.

### **Diagnostic labels: what are statins for?**

In these data there is lots of talk about problems for which statins are needed. As noted in the paper above, these problems are of two broadly defined types, cholesterol and heart problems, and the roles these two types of problem play in participants’ accounts

of needing statins are very similar to one another: both are presented as current problems necessitating treatment. This similarity is at odds with the marked and widespread distinction in biomedical research and practice between two kinds of problem exemplified within a current UK guideline [NICE 2014] about preventing cardiovascular disease (CVD): guidance relating to ‘people who have a 10% or greater 10 year risk of developing CVD’ in the future differs from guidance relating to ‘people with CVD’, implicitly a current problem. Throughout this guideline, the enterprises of advising and treating these two groups of people are referred to respectively as primary and secondary prevention, and these two different approaches are used within the document to identify the groups of people for whom they are recommended. This close connection in a biomedical document between the condition and the treatment it necessitates mirrors the connectedness of a condition and a need for treatment within my participants’ accounts.

In another respect, however, ‘doctors’ and ‘patients’ accounts differ: they accord different roles to cholesterol. Although the NICE guideline’s title begins with the words ‘Lipid modification’, and its guidance includes quantitatively specified cholesterol targets, reducing cholesterol is presented as a means to an end, a way to promote ‘the ... prevention of cardiovascular disease’. In this biomedical narrative, then, statins are for preventing future illness. The supporting evidence cited within the NICE guideline makes clear that to the authors, prevention means making a future illness less likely; their guidance explicitly centres on the assessment and reduction of CVD risk, and cholesterol is cast as a risk factor to be factored into risk assessment and modified in order to reduce risk. In contrast, as the data presented in the paper above illustrate, people who are offered statins talk about cholesterol as a problem in its own right; the paper offers a detailed description of the processes of reification and evaluation through which cholesterol comes to constitute a condition that needs treatment, processes particularly visible within the accounts of participants who are taking statins.

This description builds on and extends a large body of research about how people decide about medication. One of the ways in which the paper extends that body of research is by taking a close look at ‘what statins are for’ in the data, and then comparing this with ‘what statins are for’ in biomedical writings and practice. This comparison shows that the reason patients consider taking medication is not necessarily the same as the reason why doctors prescribe it, and hence points to a need for social

scientists to acknowledge the potential difference between the two reasons. Eborall and Will [2011] offer an example of this acknowledgement; writing about their findings from a study of decisions about aspirin, another medication recommended in biomedical guidelines for CVD prevention, they specify that they are studying the way patients talk about prevention and risk in accounting for their medication decisions. In papers about other studies, however, references to participants as, for example, receiving ‘prescriptions for hypercholesterolaemia’ [Crinson et al 2007] or ‘antihypertensive drugs’ [Benson and Britten, 2002; Morgan and Watkins, 1988] tend to conflate two framings of the problem being treated, the doctor’s and the patient’s, and tend to imply that the authors themselves reify raised cholesterol and blood pressure levels, casting hypercholesterolaemia and hypertension unproblematically as conditions or chronic illnesses. Saukko et al [2011], too, describe their study participants as considering ‘cholesterol lowering statins’, although elsewhere in their paper the authors discuss the rise and fall over time of the biomedical establishment’s reification of ‘cholesterol’; they explicitly restrict their own use of the term ‘hypercholesterolaemia’ to writing about a small group of people offered statins because of inherited, unusually high cholesterol levels.

Reading Saukko et al’s account alongside the authors’ other paper from the same study [Farrimond et al 2012], which focuses on the way participants understand ‘high risk’, illustrates the need for further clarification; these two papers present separate accounts, and so do not highlight the problematic articulation between considering medication ‘for cholesterol’ and considering it ‘for risk’. To build plausible inferences about what is going on when people talk about what statins are for, social scientists need to be explicitly reflexive about their own standpoint and its relation to the standpoints of patients and doctors regarding entities like cholesterol and risk.

Like the papers mentioned above, the study presented in the thesis looks primarily at the standpoint of a person who is offered statins, insofar as interview data can be used to explore interviewees’ standpoint. The thesis also draws on my own standpoint as a doctor (for example in the biomedically framed account of prevention given in Chapter 1) to construct a theoretically informed story within which the different voices that offer differing accounts are carefully specified. This construction work can be seen as opening a black box in which many other researchers leave the conditions for which people say they take medication. The methodological approach here, in keeping with the

ontological assumptions broadly underpinning the sociology of diagnosis, is directed at examining the various different diagnostic labels used by different groups of people, and exploring the role of these labels in accounts of medication decisions and practices. This is different from the approaches advocated by researchers who seek to open the same black box within accounts of medication decisions and practices in order to study not the label but the disease or condition itself.

### **Conditions that necessitate treatment: real to whom?**

‘Opening the black box’ is a central goal in Timmermans and Haas’ [2008] call for the delineation of a sociology of disease, and they make clear what kind of object they expect to find in there: they express regret that ‘sociologists are reluctant to attribute ontological value to conditions that appear “natural” to clinicians and patients’, and suggest that ‘clinical endpoints ...would add a bottom line health dimension to a sociological analysis’. This statement indicates the same high regard for quantitative health information that I describe and discuss in Chapter 3, drawing on data about the way people use numbers in talking about their health and health behaviours. Respect for numbers contributes to a positivist stance that frames test results and other clinical endpoints as context neutral; as well as being implicit within Timmermans and Haas’ account, this stance is visible in the data, surfaced for example by approving references to *‘the hard evidence’* of cholesterol levels that *‘are telling me .... what [my] body’s doing’*. Timmermans and Haas use the example of ‘people treated for high cholesterol’ as one illustration of their recommendation that ‘sociologists should become experts in bio measurements’. If attainable, this expertise would doubtless deepen sociologists’ understanding of the way ‘conditions’ such as ‘high cholesterol’ might come to ‘appear “natural” to clinicians’, although it would perhaps be less likely to shed light on the way cholesterol appears to patients. What seems far more contentious is the attribution of an implicitly stable ontological value to such conditions.

My participants use ‘conditions’ in their accounts in ways that render them conceptually indistinguishable from the ‘diagnostic categories’ discussed by Jutel and Nettleton [2011]; functionally, a condition or diagnosis serves as an indispensable constituent of ‘needing medication’ in these accounts. By describing ‘high cholesterol’ as something ‘people [get] treated for’, Timmermans and Haas unwittingly provide an example of the reification of cholesterol, and of the circular relationship between ‘having a condition’



and ‘needing medication’. This reciprocal relationship is also visible in the data, for instance in the data excerpt cited in Chapter 3, where a couple, Don and Mary, talk about taking medication for a condition – Don says ‘*we’ve had more than one... episode, haven’t we, Mary, of where you needed medication*’ – but not wanting to take it for what Don describes as ‘*just....maintaining a healthy body*’. Having a condition, then, legitimates taking medication, and needing medication is a way of legitimating an ‘*episode*’ as a manifestation of a condition, implicitly according it what Timmermans and Haas call “‘natural’ ... ontological value’.

Timmermans and Haas recommend that sociologists should overcome their reluctance to adopt Mary and Don’s standpoint, but reasons to question this recommendation are easy to identify in the context of CVD. Cardiovascular disease is a group of conditions or diagnostic labels for which stable, context neutral endpoints are particularly difficult to identify. In this respect it exemplifies many aspects of the transformative process characterised by David Armstrong as Surveillance Medicine [1995]. Because they are common, cardiovascular conditions are an extremely popular focus for research, some of it funded by commercial organisations that develop medication and other technologies, or by patient groups. These agencies are among the drivers Conrad [2005] identifies as engines of medicalisation, and are prominent in Clarke et al’s [2010] account of biomedicalization; both these models challenge the biomedical framing of disease entities as having “‘natural’ ... ontological value’. Thus CVD offers a particularly clear example of the constructed nature of disease that is a central theme of Armstrong’s work, as discussed in Chapter 1. At the end of his essay [2012a] contrasting the explanatory power of a stable ‘biological body’ and that of a situated, socially constructed model, Armstrong warns social scientists who seek ‘a rapprochement ...between biology and sociology’ to guard against allowing biology to dominate the relationship: ‘one explanatory framework can become subservient to another’. This warning underlines the importance of reflexivity and transparency about the explanatory framework one is using, features I emphasise in the previous section of this chapter when discussing different framings of cholesterol; it is a warning that seems particularly pertinent to sociologists of disease.

Several examples from my data illustrate the fuzzy boundaries of heart disease and the way that new and evolving technologies contribute not only to expanding these

boundaries but also to blurring them further. The group of participants who identify themselves as having heart problems includes not only people who offer a dramatic account of a terrifying episode in which they suddenly felt very ill, had severe pain or collapsed, but also people who describe having heart disease diagnosed by tests after seeing their doctor about very mild symptoms. David is a member of this second group, yet this excerpt from his account shows that he is in no doubt that he has got a heart problem, even though he has never felt unwell:

*David: I didn't have any trouble fortunately, it was just pure chance that they found the problem with the arteries. I had a erm, what do you call it, an angiogram which they just said was routine, they won't find anything but they did, they, you know they said you've got four major blockages... I had no pre warning about it at all, so I was very very lucky*

From a medical standpoint, David has got CVD; the NICE guidance [2014] would characterise him as a candidate for secondary prevention. This framing accords with his own, as indicated by the excerpt above and by the account elsewhere in his interview of the reason he takes statins: *'they found things, so I've got to do what I'm told'*. By stating that *'the sociology of disease focuses on how social processes affect the severity or course of diseases'*, Timmermans and Haas imply that social processes and diseases are separate entities that may affect one another, but in the framings proposed by Armstrong, David's CVD would not exist without processes which are clearly social; a few decades ago he would have been a healthy person, who might or might not have died in the future from a heart attack. His story thus challenges a framing centred on *'real'*, implicitly stable diseases, fitting far better with Jutel and Nettleton's [2011]'s point, in their discussion of the sociology of diagnosis, that *'the category and process of diagnosis are.... inextricably interlinked and mutually constitutive'*.

Comparing David with another participant who had a test which *'found things'* wrong with his heart helps highlight a different inextricable interlinkage, between *'disease'* and the need for treatment. Henry felt perfectly well but a screening test offered through his work led him to take statins:

*Henry: The thing that came out was that I had ... signs of atherosclerosis and slightly raised cholesterol*

That these ‘*signs*’ function in his account as a problem in need of treatment is clarified by his reply to a later question about which of the two he decided to take statins for, the heart test result or the cholesterol: ‘*It was the heart thing mainly, actually*’. Concern about the likelihood or risk of future illness related to ‘*the heart thing*’ is invisible in his account, as it is in David’s; the similarity between their two accounts illustrates the way new technologies can blur the boundaries that delineate ‘disease’. In a biomedical article about one such new technology for coronary artery imaging, the type of procedure that Henry describes undergoing, Chahal, Levsky and Garcia [2016] present the images it generates as useful for making risk estimates more accurate, and hence for informing recommendations about statins and other interventions for primary prevention; but my findings strongly suggest that people will construe a ‘high risk’ result from this new test as a current problem with their heart. Like Henry, they are likely to regard statins as necessary treatment for that problem. This seems an insuperable obstacle to Timmermans and Haas’ aspiration to study ‘real diseases’ and reified ‘clinical endpoints’, stable entities that exist independently of ‘social processes’ although potentially affected by them. Rather than adopting the positivist ontological assumptions that underpin, for example, the biomedical framing of primary and secondary CVD prevention as applicable in two clearly distinct situations, Henry’s and David’s respectively, sociologists of disease might more usefully engage with the growing biomedical voice that questions these assumptions and acknowledges that CVD has been transformed by the rapidly extending medical gaze that Armstrong [1983] first discussed over 30 years ago. This engagement is one of the topics discussed in Chapter 8 of the thesis.

Considering the similarity between David’s and Henry’s accounts also helps to foreground medication decision making and other medication practices; placing these practices centre stage, with diagnostic labels and the ‘real diseases’ those labels represent relegated to supporting roles, is a key move within the argument constructed and presented in the thesis. The effect of this move is similar to that of the approach Mol [2002] describes in her account of an ethnographic study of the multiple diagnostic processes used to evaluate the severity of a patient’s atherosclerosis: she emphasises that these processes and practices function to provide an answer to the question “‘what to do?’”. Some of Mol’s specified goals are similar to those outlined by Timmermans and Haas; like them, she seeks to talk about bodies rather than perceptions of bodies, so

as to breach ‘the disease/ illness distinction’, and like them she seeks to engage with ‘reality’, contrasting her own ontological approach with ‘perspectivalist’ methodologies that leave ‘the object observed ...untouched ... only looked at ...in the middle of a circle’ of ‘a crowd of silent faces’ [p12] whose perceptions of the object are what is studied. But unlike Timmermans and Haas’ black box of ‘real diseases’, Mol’s silent circle contains multiple enactments of diseases; her ontological approach conceptualises the ‘real’ atherosclerosis as a collection of ‘objects in practice’ [p149], enactments of multiple co-existing entities that are all called atherosclerosis [p150].

Mol’s approach is compatible with Jutel and Nettleton’s [2011] warning against attempting to attribute to diagnostic categories (or conditions) a ‘natural’ ontological value independent of the process of diagnosis. Jutel and Nettleton’s framing of diagnostic category and diagnostic process as ‘mutually constitutive’ is mirrored by Mol’s account of reality as a product of practices: ‘the crucial question [is] ...what is being done and what, in doing so, is reality made to be?’ [p160]. The closeness of these two framings is highlighted by an account offered by Gardner et al [2011] which uses many elements of both, framing as ‘patchwork diagnosis’ both the multiple processes that lead to their participant’s treatment for a heart problem and the heart problem itself. Thus this heart problem is presented both as a multiply enacted object in practice, and as a diagnosis as category that is produced by diagnostic processes. Mol’s, Gardner et al’s and my participants are all working to answer the question ‘what to do?’ – to these other authors, as to me, the object of study is ‘what is being done’ in order to answer that question. Bracketing Mol’s further concern about ‘what ...reality is made to be’, the following two Findings chapters focus on what is being done when people enact deciding about pills and accomplish regular pill taking. Chapters 3 and 4 have presented findings about the work participants do to establish that their pill taking is necessary. In Chapters 5 and 6 I explore the role this necessity plays in accounts of pill taking.

## Chapter 5: Statin-taking as a threat to a moral identity

*Eileen: We never take painkillers do we? I would have to be really, poorly you know.*

*Mike: We have taken paracetamol a couple of times, but we're not really regular consumers*

### Introduction

The previous two chapters build a picture of the way 'needing statins' is constituted in the accounts of participants who have been offered them. This chapter moves on to consider how 'need' is used by participants in accounting for their medication decisions and health practices; the claim is that 'need' is used to legitimate regular pill-taking. The paper that follows discusses why pill-taking in general, and statin-taking in particular, require legitimation, and gives a detailed description of the morally coloured identity work involved in accomplishing it. Participants' talk about pill-taking is cast as contributing to a presentation to themselves (often co-constructed during couple interviews with their partner) as well as to the interviewer. This methodological approach enables the data to be used as a source of clues to the discourses that determine whether or not an account is comfortably presentable.

In the paper, I describe the complex tangle of calibrations participants undertake in order to present themselves as paying just the right amount of attention to pain or discomfort, collecting the right amount of information but not too much, heeding doctors' advice sensibly but not slavishly, and adopting healthy 'lifestyle choices' without being *'faddy'* or failing to enjoy life. Each of these closely articulating calibrations involves negotiating a collection of moral imperatives which often conflict with one another. By foregrounding these discursive framings, the paper situates itself within a body of research and debate about healthism and the way that taking pills can affect identity. My account also draws on research that explores threats to moral identity in quite different contexts within health care; for example, in a study of the way parents talk in interviews about their encounters with health professionals, Baruch [1981] presents his interview data as helping interviewees to 'establish the rationality of their actions and also their own reasonable and moral character'. This portrayal is echoed within the approach I use, framing my interview data as a collection of situated

performances in which participants work to present and defend their competence and moral adequacy.

This paper highlights a potential tension between two rival tropes both of which centre on the idea of ‘a pill for every ill’. An anti-pill trope makes sense of the framing of pill-taking as a threat to a presentable identity, while a trope about medical progress, also widely referenced in these data, makes sense of the fact that most participants do report needing lots of pills. The visibility of both these tropes within a single interview, and the lack of visible tension between them in participants’ accounts, supports Will and Weiner’s [2014] description of people referencing a ‘sustained multiplicity’ of discourses in talk about healthy living, moving smoothly between these apparently conflicting discourses. The paper takes a close look at what this ‘moving smoothly’ entails, generating a picture of participants whose apparently smooth movement is produced by a complex process of paddling hard under the water, water which is full of potential obstacles to the goal of constructing and presenting moral adequacy.

**Paper 4: What is wrong with “being a pill-taker”? The special case of statins**

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## **Abstract**

In an interview study of decision-making about statins, many participants said they took pills regularly, yet described themselves as 'not really pill-takers'. This paper explores this paradox and its implications. The practice of pill-taking itself can constitute a challenge to the presentation of moral adequacy, beyond the potential for rendering stigmatised illnesses visible. Meeting this challenge involves a complex process of calibrating often-conflicting moral imperatives: to be concerned, but not too concerned, over one's health; to be informed, but not over-informed; and deferential but not over-deferential to medical expertise. This calibration reflects a broader tension between rival tropes: embracing medical progress and resisting medicalisation. Participants who take statins present them as unquestionably necessary; 'needing' pills, as opposed to choosing to take them, serves as a defence against the devalued identity of being a pill-taker. However, needing to take statins offers an additional threat to identity, because taking statins is widely perceived to be an alternative strategy to 'choosing a healthy lifestyle'. This perception underpins a responsabilising health promotion discourse that shapes and complicates the work participants do to avoid presenting themselves as 'pill-takers'. The salience of this discourse should be acknowledged where discussions of medicalisation use statins as an example.



## Introduction

*'The....scenario - of whole populations taking a daily tablet to mitigate against unhealthy lifestyles - is far from attractive'* (Smeeth and Hemingway, 2012)

Smeeth and Hemingway's comment, written in response to a recommendation (Mihaylova et al, 2012) that statins should be offered at a lower threshold of cardiovascular risk than before, indicates a distaste for the idea of widespread pill-taking. Such distaste has become a trope over several decades, yet during these same decades people have come to take more pills than ever. This apparent paradox is explored in the study reported here, which looks at how participants talk about statin decisions. Many participants say they take pills regularly but also say they are not 'pill-takers'. This article explores what people mean by 'being a pill-taker', how they avoid presenting themselves in this implicitly undesirable way, and why it is particularly hard to legitimate statin-taking.

Although offering statins to more people has been incorporated into health policy in the UK (NICE 2014), the recommendation is the subject of ongoing controversy (Parish et al, 2015). In part, this controversy reflects a clash between two different discourses, with 'a pill for every ill' (Huxley, 1932) cast as a desirable goal of medical progress within a primarily-biomedical discourse, but as 'the spectre of a medicalised and medicated society' (Crawford, 1980) within a social science discourse. Central to this clash is an extension of the medical gaze outward from its old focus on sick individuals to encompass the whole population, redefining an 'ill', or medical problem. Armstrong (1995) describes this extension as making a central contribution to the evolution of 'surveillance medicine'. His thesis is illustrated by considering cardiovascular disease and statins: as well as having illnesses like heart attacks or angina, individuals may now be diagnosed as being 'at risk' of future heart attacks and offered statins to reduce this risk.

From the 'medical progress' perspective implicit in most biomedical research and practice, an expansion of the group of people who have an identifiable, treatable medical problem is to be welcomed, increasing the number of people who can benefit from medical interventions. Within this framing, 'non-compliance' with the proffered

interventions – for instance, less than 50% of people prescribed statins still take them two years later (Jackevicius et al, 2002) – is ‘a major problem in health care’ (Vermeire et al, 2001), one for which solutions are sought by many researchers. Haynes et al (2008), for instance, review quantitative studies assessing interventions intended to overcome what Vermeire et al cast as ‘barriers to adherence’; in the context of statins and cardiovascular screening, McNaughton and Shucksmith’s (2015) qualitative study seeks ‘reasons for (non)compliance’ with the risk-reducing interventions offered.

A countervailing narrative highlights the potential harms of the expansion of medicine’s remit into the management of ‘problems’ such as cardiovascular risk, and frames this expansion as medicalisation. As well as harms that medical diagnoses and interventions can do to individuals, including the social and psychological effects of being assigned a liminal, ‘at risk’ status (Aronowitz, 2009; Scott et al, 2005), this narrative highlights wider concerns about governmental power and ‘healthism’ (Crawford, 1980), and reframes ‘non-compliance’ with medical advice as one possible product of a collection of self-regulation practices (Conrad, 1985). For instance, in a synthesis of qualitative evidence that highlights various concerns about harms of medication, Pound et al (2005) describe these concerns as contributing to ‘resistance’ to medication.

Britten et al (2015) offer a nuanced account of the positioning of potential patients or consumers in relation to the two competing framings of ‘a pill for every ill’, describing the way patients involved in evaluating a new drug for their own condition look closely at its possible benefits and consider a wide range of potential caveats, rather than simply demanding or resisting additional medication. By repositioning ‘patients’ as ‘critical reflexive agents’ (Williams and Calnan, 1996), such accounts situate themselves within a literature on pharmaceuticalisation which foregrounds the agency of potential pill-takers. This emphasis is developed by Dew et al’s (2015) move away from focusing on medication as an object to be accepted or rejected, instead examining moral evaluations of medication practices.

Adopting this focus on the practice of pill-taking (rather than on the pills themselves), this article considers the morally-infused identity work involved in one health decision:

deciding whether to take statins. A substantial body of research examines statin decisions, documenting understandings of cholesterol (Sachs, 1996; Polak, 2016) and risk (Crimson et al, 2007; Farrimond et al, 2010) and the way these get used in decision-making (Gale et al, 2011; Polak and Green, 2015); but neither these nor more general accounts of resistance to medication or barriers to adherence seem adequate to explain why Smeeth and Hemingway (2012) find the ‘pill for every ill’ scenario inherently *‘unattractive’*. An alternative explanation for their widely shared distaste centres on the identity potentially conferred by the practice of pill-taking. Eborall and Will’s (2011) analysis of decisions about aspirin highlights the difference between explanations centred on the pills and their effects, and explanations centred on pill-taking as a practice. The authors attribute ‘dislike of taking pills’ to the standardly-reported range of concerns about the medication itself (Pound et al, 2005), which they describe as mitigated by the reassuring familiarity of aspirin and balanced against its perceived benefits; they then explicitly distinguish this pill-centred ‘dislike’ from the wish to ‘avoid being seen as a “pill-popper”’. This identity management is central to the account presented here.

‘Identity work’ has long been a topic of analysis in studying the way people accommodate their chronic illnesses within a presentable biography (Radley, 1989). Resisting medication is often portrayed as a way of resisting an illness label; concerning asthma, for instance, Adams, Pill and Jones (1997) summarise an extensive literature (dating back to Goffman’s work on stigma) in their account of the work people do to avoid making their illness visible by using medication. In the same way, people might resist taking statins in order to avoid identifying themselves as having heart disease, and Farrimond et al (2010) found that even ‘being high risk’ was an identity that their participants worked to minimise or normalise. However, this account does not solve the puzzle highlighted here: people who comfortably talk about their health problems and describe taking lots of pills emphasise, like Eborall and Will’s participants, that they are ‘not pill-takers’. This article explores the way pill-taking constitutes a direct threat to a presentable identity, not just a threat mediated by spoiling a ‘healthy’ status: there is something inherently ‘wrong’ with being a pill-taker in general and a statin-taker in particular.

## **Methods**

Data were generated by interviewing 34 people who had been offered a statin: participants (aged 53–87; 12 women; occupations including cleaner and company director) were recruited and interviewed face-to-face in community settings in East Anglia between 2011 and 2013. The choice to use non-clinical settings reflected the perception that decisions about long-term medication are distributed, involving multiple interactions rather than being enacted within clinical encounters (Rapley, 2008). An unforeseen advantage of conducting interviews at home was that twenty-two participants were interviewed with their partner. As discussed by Polak and Green (2016), these couple interviews offered additional analytic purchase; they functioned as a hybrid between focus groups and individual interviews, facilitating exploration of the tensions negotiated and tacit resources drawn on in the process of making decisions, while still providing a setting private enough to allow participants to discuss sensitive topics.

Invitations to participate were made through community groups such as lunch clubs and an exercise class, and snowballing from initial participants. All interviews were conducted by the author, recorded, and transcribed verbatim. They were semi-structured, using a brief topic guide which included questions on participants' health and how they looked after it, where their knowledge about health came from, and their decisions about and use of medication in general and statins in particular. Ethical approval was obtained from the author's institution. All names in this paper are pseudonyms, and identifying material has been removed.

All participants identified themselves as 'well' when interviewed, although 16 had previously suffered a heart problem requiring urgent hospital admission (some did not specify the precise diagnosis, or expressed uncertainty about it); all these are referred to here as having had a heart attack. The analysis presented here does not compare people who had had heart attacks with people who had not; despite the clear biomedical distinction between these two groups, offered 'secondary' and 'primary prevention' respectively, Lytsy, Burell and Westerling (2010) found no difference between them regarding statin decisions. Polak (2016) supports this finding,

highlighting the slippery distinction between ‘prevention’ and ‘treatment’ in accounts of medication decisions, and the functional similarity between cholesterol and heart problems as reasons for taking statins.

Almost all participants took regular medication. In the analysis presented, differences between such medications are not highlighted except in the section specifically concerning statins, where a comparison is made between the 23 participants taking statins and participants not taking them.

Analysis employed elements of a grounded theory approach, in an iterative process whose rigour was increased by regular discussion with colleagues about coding decisions and analytic direction. The data were used as a source of insight not into what people thought or did, but into the discursive frameworks which make sense of what is said, an analytic approach exemplified by Green et al (2003) in their use of group interview data to illuminate the ‘rules of thumb’ governing food choices, rather than the choices themselves; and by Eborall and Will’s (2011) exploration of the clashes of norms which inform decisions about preventive medication. Radley and Billig (1996) advocate this focus on participants’ accounts, rather than on their health beliefs, as a way to study the way a presentable identity is constituted. Here, participants’ accounts of their medication practices are cast as work they do to present themselves in a way they are comfortable with, and specifically are used to explain why presenting oneself as a ‘pill-taker’ is uncomfortable.

## **Findings**

### **Too many pills: what is wrong with ‘being a pill-taker’?**

Larry, taking statins since his heart attack, exemplifies a paradox presented by many interviewees: although he describes taking four different pills every day, he says ‘*I have never been, really a pill-taker*’. His statement seems to reply to an unspoken accusation that he takes too many pills; the implication is that pill-taking is bad. This implication is supported by the finding that taking lots of pills is almost always presented as something done by other people; when talking about themselves, most people emphasise how few pills they take. The following exchange between Violet and her

husband Jim exemplifies this: Jim responds with a defensive ‘*but –*’ to Violet’s story about some (other, unspecified) people taking too many pills for too long, pills they may not ‘*need*’. He is asking Violet to reassure him by agreeing that he is different from those others because he has reduced the number of pills steeply since coming out of hospital.

*Interviewer: Why would you say fewer pills is better?*

*Violet: Well because sometimes you don’t need all the medication....*

*Jim: but the things I am on are just the two little pills in the morning I take now, don’t I?*

Talking more generally about her antipathy to pills, Gill explicitly references the trope that ‘a pill for every ill’ is a bad idea:

*Gill: Our lives are, run by tablets now....whatever’s wrong with you, you take a tablet*

*Interviewer: and is that a good thing?*

*Gill: no because they don’t get to the root of the problem....the last 20 years now, everything is pills*

This anti-pill trope is prevalent in the data. Its pervasiveness is perhaps illustrated by the fact that it is unthinkable that Yvonne would say she does ‘*like taking drugs*’, at least in this context:

*Yvonne: I don’t like taking drugs*

*Interviewer: Can you say why that is?*

*Yvonne: Because it’s abnormal to the body*

Gill’s and Yvonne’s mentions of concerns that taking pills is ‘*abnormal to the body*’, or that ‘*they don’t get to the root of the problem*’, could be construed as indicating perceptions of pills as inherently undesirable objects, and thus as echoing the broad findings of much qualitative research on accounts of perceptions of medication. But these concerns are mentioned only when prompted by the interviewer’s questions, suggesting instead that their primary role in these accounts is to rationalise a morally-coloured distaste not for the pills themselves but for the practice of pill-taking.

Distaste for pill-taking is indirectly visible in an extract from Kathy's interview. Kathy is an exception to the general rule that taking lots of pills is something other people are described as doing, not oneself; she speaks at some length about the complexity of her pill regime, which involves taking '*on average about 25 tablets a day*':

*Kathy: When people say I can do without them, I do wonder if there is as much wrong with them as they say there is, because most of the people I know who take them really really need them....They do react badly if they don't [take them]*

Two features of this excerpt provide insight into the moral work of pill-taking. First, Kathy presents her account framed in a defensive reply to what '*people say*'; she is one of the people who '*do react badly*' if she doesn't take them, the '*do*' emphasising the defiant tone of her statement. Second, her switch within this statement from the first to the third person, from people suggesting that she herself '*can do without*' pills, to this applying to '*people I know*', can be seen as a device for talking about something a bit embarrassing or shameful; Kathy's use of this device suggests that pill-taking is inherently a bad thing, uncomfortable to admit to. The way she protects herself against the discomfort of this admission is by emphasising that she '*really really need[s]*' her pills, and so is different from someone who takes pills she does not need; '*need*' is presented as an impregnable defence against the tacit accusation that she takes too many pills.

Exactly what constitutes need is often hard to pin down; Don and Mary's exchange illustrates a common circularity in the data between the definition of need and the definition of '*a condition*':

*Don: If you can keep yourself healthy....then why should you take tablets, for anything at all?*

*Mary: But if you have a condition you would –*

*Don: Well if you have a condition well that's right....we've had more than one....episode, haven't we, Mary, of where you needed medication. So that to me is a different sort of situation, to the one which I'm in, which is just....maintaining a healthy body.*

Like Don, many interviewees speak of 'need' as a binary entity which is either present or absent, and the condition for which pills are needed is often left unspecified, although explanations like Kathy's '*they do react badly if they don't [take them]*' are sometimes added. However, such explanations are not offered for taking statins; as one participant explains, statins '*are not immediate effect type of pills*'. Instead, most present themselves as needing statins for two reasons which often co-exist: first, they need to treat their cholesterol level, which is thus reified as a condition, and second, a doctor has said they need to take them.

*Debbie: They tested your cholesterol....*

*Keith:....and they said it was about 6.9 and they put me on [statins]*

*Larry: He pointed his finger at me and he said 'If you want to live a normal life you take the tablets and you'll live to be an old man....Don't take the tablets and who knows what will happen'. So, I have always taken my tablets*

Crucially, neither Keith nor Larry presents himself as choosing to take statins; instead both imply that they need to take them. Rather than seeking to pin down the meaning of 'need', considering its function in these accounts of medication-taking gives useful analytic purchase: participants use 'need' to protect them from the unwanted 'pill-taker' label, and what constitutes 'need' in this data is absence of choice. In the next excerpts, the distinction between needing to take pills and choosing to take them is indicated by Mike's use of the word '*consumers*', and by Ron's mention of '*affecting*' pills. These terms serve to emphasise that the speakers themselves are not people who choose to take pills:

*Eileen: We never take painkillers do we?*

*Mike: No.*

*Eileen: I would have to be really, poorly you know.*

*Mike: We have taken paracetamol a couple of times, but we are not really regular consumers are we*



*Ron: I have never really taken pills have I...I've always been quite sporty....I have never affected pills*

The context in which Ron makes his remarks is illuminating: he is responding to an invitation to tell the story of how he came to be taking pills, and most of his long answer describes his many sporting achievements in the past. By answering a question about pill-taking with a description of himself as a 'sporty' person, he indicates a tacit assumption that being the kind of person who 'affect[s]' (or chooses) pills is the antithesis of being 'sporty'. Thus accounts of pill-taking articulate with concerns about identity: Ron's identity as an admirably sporty person is not threatened by the fact that he now takes several kinds of pill, because he takes them only because he needs them. His story, like Eileen and Mike's exchange, implies that some (unspecified, other) people choose to take pills they do not need; 'needing' pills and 'choosing' to take them are presented as mutually exclusive. Thus talk about need can be seen as a shield against an unwanted identity, helping someone who takes pills to avoid presenting herself as a pill-taker; she only takes pills because she needs to, so cannot be accused of taking too many. However, this highlights a challenge: judging how many pills is 'just right' rests on a complex process of evaluation.

### **Sensible pill-taking: the challenge of calibration**

In this data, health practices such as pill-taking are frequently evaluated by comparisons with largely-tacit norms specifying, for instance, the right amount of concern about health. Barbara illustrates this, in her morally-coloured account of trying to avoid being 'stupid' and 'over' reacting to 'little' pains:

*Barbara: You can imagine such awful things that a little ache and pain, and I try not to be stupid about it...I mean, not, not to get , over worked-up about everything*

Several interviewees indicate that calibrating just how worked-up one ought to get is tricky, and often involves balancing competing norms. Like most participants, for instance, Neil begins by making it clear that he tries not to take pills:

*Neil: I avoid pills, I wouldn't take pills for a headache not unless I had to*

Then later he expands on this in a way which helps explain what he means by '*I had to*', after describing having realised after his heart attack that for a while he had been ignoring pains which were probably early warnings of trouble. The next excerpt highlights the tension between responding to '*continuous... pain*' and not responding to '*a little niggle*'; Neil contrasts his own prudent identity with the unacceptable one of being '*just that way inclined*':

*Neil: I have learnt not to put up with something....if you've got a pain and it's continuous, I don't mean a little niggle because I've got a mother-in-law like that, she will phone up and go for anything, she's just that way inclined*

This tension is further illustrated in an exchange where Claire and Walter work to reach agreement about the right time to call an ambulance if she gets chest pain after her recent heart attack. Here a three-way balance has to be struck, involving obeying doctors' advice as well as stoicism and sensible caution:

*Claire: We called the ambulance out twice and it goes against my grain that I don't want to be you know like Peter and the Wolf.*

*Walter: But you don't get a choice if you are in pain you cannot question that, because you don't get a second chance.*

*Claire: Well it is that little puffer if you take it twice you need to call and I am embarrassed to ring up, you know, I just think that I am not ill enough.*

Doctors' advice is the subject of a further tension to be negotiated, between accepting it sensibly and obeying it unquestioningly. Many interviewees imply that if a doctor says you need the pills then it is '*silly*' not to take them:

*Ann: A friend some years ago....I thought 'oh you silly woman, you've been prescribed them, you should stick to it', but, she gave up*

Similarly, the way Frank speaks about being '*a sort of person*' who heeds authority suggests he views this as a positive facet of his identity, rather than an unfortunate weakness:

*Frank: I'm not a sort of person who gives up on prescriptions – if somebody's told me I ought to take something, I take it*

But deference to medical authority can be evaluated differently: Fiona, for instance, says that it is only thanks to luck that her husband Ron's obedience, here framed as rather overly deferential, has not resulted in 'any nasty experiences'.

*Fiona: Ron does accept things like that. He thinks doctors are gods and if they say something he'll do it, and, but you've been lucky, because you've never had any, any nasty experiences with pills have you?*

Thus identity shapes and is shaped by health practices such as responding to doctors' advice, and these practices are themselves informed by a collection of often-conflicting moral discourses.

The alternative to over-deference to doctors' orders is to collect information from other sources. However, this too requires calibration to avoid doing either too much or too little. Two contrasting excerpts illustrate this: Fiona criticises herself for not seeking information about statins, while Colin defends himself against an implicit charge of excessive information seeking, distinguishing the way he 'sometimes take[s] an interest' from 'hypochondria'.

*Fiona: I must admit it was very bad of me because I didn't really look them up to see what they were, you know*

*Colin: I probably read it somewhere*

*Interviewer: So you...read a bit about such things*

*Colin: I don't – I'm not a hypochondriac, but if – I sometimes take an interest in these things*

Collecting too much information thus risks earning the undesirable label of 'hypochondriac'. Indeed, several interviewees talk about too much information as liable to cause hypochondria, producing imaginary ailments. The list of potential side-effects in the pill packet was often mentioned as particularly likely to have this effect:

*Eileen: If you read all the side effects, you wouldn't take them.*

*Mike: Well that's right. There are so many side effects, you know, you would be coughing and scratching!*

*Eileen: Pages like that, I don't know, we don't read them.*

Claire and Walter, too, describe throwing away these information leaflets, because, as Walter says, 'you can bog yourself down can't you with the information'. To emphasise that throwing away the leaflet is a sensible precaution against the possible bad effects of reading it, they tell the story of a relative: she did not take this precaution, but instead allowed herself to be persuaded by the leaflets that pills were giving her side effects, thus depriving herself of the benefits she would have gained from taking them:

*Claire: She read all the leaflets, not to find out what it would do good for you, but the side effects, you see.*

*Walter: That was her main priority, side effects...*

*Claire: and she would say it doesn't suit me, tried it a couple of times and –*

*Walter: – that was it, bang.*

*Claire:....obviously her health declined.*

Thus gathering too much information may lead someone to take fewer pills than she needs, as well as (in the standard picture of a hypochondriac) leading him to take too many pills because of too much concern about his health, as Larry describes his father doing:

*Larry: [He] was on something like 22 tablets a day....but he was a hypochondriac*

Concern about one's health is the subject of another tricky calibration process. Many people reference general knowledge about healthy eating, presenting themselves as careful and hence responsible (doing what 'you have to'), as Don does:

*Don: I wouldn't, have cakes, and so on, or a lot of pastry...sugar, it's hidden in just about everything, isn't it?...you have to be so, so careful*

But taking too much care is 'faddy', as both Bill and Peter suggest in these extracts:

*Bill: I think people get faddy, they find something like they've got to drink 2 litres of water a day*

*Peter: You can't spend your life self-analysing... You can't become paranoid, because if you do it will dominate your whole life, and my life will not be dominated*

As well as marking one as faddy or paranoid, adopting good health behaviour is sometimes presented as being in tension with the requirement to enjoy life; Violet indicates an awareness of the need to balance these two rival imperatives:

*Violet: Well we eat lots of vegetables because we have got the allotment, don't we. Mind, Jim has got quite a sweet tooth, he likes his chocolate. We've all got vices.... I don't believe really that as you get older that you can't have some of the things that you like.... You've got to have some joys in life.*

Contextual factors like age can modify the way a 'just right' level of pill-taking gets determined; different participants use differing yardsticks to assess the number of pills they take. This difference is visible in the contrast between the anti-pills stance indicated by most participants and the welcoming approval of pills by just a few. These few are mostly among the oldest participants, such as Ann: describing a group of friends of her age cheerfully comparing notes about their many pills over coffee, she says the pills '*keep us going*'; needing pills is presented as normal at her age. Chris is younger than Ann, but has already reached an age at which serious illness is normal in his family, and has outlived several colleagues:

*Yvonne: A lot of your colleagues sort of flaked out in their late fifties.*

*Chris: Oh blimey there was five of us... and we were all the same age funny enough... You know I am the only one left.*

Like Ann, he shifts the balance towards the acceptability of pill-taking, saying that pills '*keep [him] alive*' and explicitly casting them as a benefit of medical progress:

*Chris: It's drugs that keep us alive now....because both my parents, they both died in their 70's....they had heart problems, but of course they didn't have the medicine....*

Both Ann and Chris seem comfortable identifying themselves as people who rely on pills, indicating no concern that they might be accused of taking too many. Chris' lack of discomfort illustrates that age is itself calibrated not only chronologically but also through comparisons with other people like oneself. In this way, Chris implicitly presents himself as old enough to need lots of pills; hence pill-taking does not threaten his identity.

These interviewees thus work to present themselves as taking just the right number of pills, a number defined by a complex set of calibrations in which several tensions are inextricably entangled: the task of making just the right amount of effort to regulate one's health involves collecting the right amount of information about one's pills, and paying the right amount of heed to doctors' advice and to information about healthy behaviours. Paying too much attention to one's health and health behaviour, or reading too much about one's condition and treatment, makes one liable to be labelled as a hypochondriac, but paying too little attention is negligent. Heeding doctors' advice (for example, advice to take pills) articulates with both self-regulation and information gathering: one aspect of self-regulation is deciding whether to follow doctors' advice unquestioningly, or whether to check it against other sources of information. These densely articulating and often conflicting moral imperatives inform medication decisions; people have to negotiate a way through the tangle in order to distinguish between their own necessary, sensible pill-taking and the way other people behave.

People who take pills are so successful at presenting themselves as 'not pill-takers' that tensions between these two identities never surface in the data. Indeed, participants within a single interview draw on discourses both of the rejection of pill-taking and of the necessity for it. For instance Yvonne and her husband Chris, who both take several pills each day, move without apparent discomfort between her comment that '*I don't like taking drugs*' and his '*It's drugs that keep us alive now*'. The

potential contrast between these two comments is a component of the broader tension between the competing tropes of rejecting medicalisation and welcoming medical progress; Gill's disapproving statement '*now, whatever's wrong with you, you take a tablet*' comes minutes before she echoes her husband's enthusiasm about the heart treatment which they say has kept him alive beyond his biblically-defined span:

*Simon: I mean I'm 72 and each day I wake up, it's a bonus really, is how I look at it—*

*Gill: three-score year and ten*

To these participants, the difference between taking pills which keep you alive and indulging in unnecessary pill-taking goes without saying; but considerable work is needed to demonstrate that their own medication practices are 'just right'.

### **Needing pills that you ought not to need: the special case of statins and heart problems**

Statins are one of a small group of drugs which are seen as dealing with a problem which could be also dealt with (or even avoided) by 'good behaviour'; it is widely-shared common knowledge that you can keep your heart healthy by exercising more and eating less. Violet is one of many interviewees who reference this knowledge, talking here about the ways (other) people deal with concern about their cholesterol level; she does not take statins herself: "*Given the option of a pill or diet I think people will take the pill.*". Violet's account of a choice between pills and diet highlights the particular accusation which can be levelled against people who take statins: taking the pills can get cast as a '*lazy*' or '*easier*' option. For a small minority of participants, this is acknowledged as an incentive for their own decision to take statins, as Jim and Geoff suggest:

*Jim: I just eat what she puts in front of me you know [laughs]. I eat what I want and the statins do the rest I suppose. It's a lazy attitude actually isn't it*

*Geoff: It's a damn sight easier [taking statins]....than running 5 miles a day and only eating vegetables*

However, most people who explicitly frame ‘*pill or diet*’ as alternative ways of addressing health concerns have declined statins. They present this decision as choosing the ‘virtuous’ option instead of the pills:

*Ed: I will do regular exercise, regular shopping at the farmers’ market, regular cooking for myself....if I can get into those regular habits, then I hope I can avoid getting into the regular habit of taking....pills*

This seems a simple statement of Ed’s preference, but can be recognised as morally-loaded in the light of background knowledge that exercise and eating in certain ways is widely regarded as good behaviour.

In contrast, very few statin-takers present pills as an alternative to healthy ‘*habits*’; indeed many cite their healthy habits as the reason for their current good health. Larry (who takes statins) does this, in an account very like Ed’s:

*Larry: I used to go to the gym regular, I have a bike which I use a lot to go shopping and things like that...so I am quite healthy as it goes*

Don makes this moral colour even more visible; he talks of ‘*just....taking care*’ despite presenting himself earlier in the interview as needing (and taking) statins:

*Don: It’s just a matter of watching, what you eat, and taking care...if you do not need these things [pills] then do not take them... if you can keep yourself healthy, in terms of.... exercise, and a good...balanced diet....then everything should work ok, shouldn’t it?*

Don’s ‘*everything should work ok*’ suggests that good health behaviour deserves the reward of good health, an idea highlighted by the anger Peter expresses about having a heart attack in spite of his ‘*healthy lifestyle*’:

*Peter: There was all sorts of things that we didn’t do, so when I had a heart attack I was really annoyed because....we were not doing the bad things anyway, and we were eating lots of fruit and....vegetables and, all those things you are supposed to do for a healthy lifestyle, and I still had a heart attack*



Thus almost everyone interviewed here emphasises their own good behaviour, whether or not they take statins, as Peter does. This linkage of health and behaviour inevitably implies that, at least in the context of heart disease, an illness is not just unpleasant in itself; it may also be an unwelcome indication of failure to behave well enough. This implication helps explain the discomfort or reluctance with which people speak about pill-taking even when it is clearly 'needed' because of an unequivocally-diagnosed medical problem. In the next excerpt Vic, another statin-taker, makes efforts to mitigate this discomfort, both by playing down the size of the problem (he hesitates before mentioning his heart attack and then refers to it as '*the little scare*') and by emphasising his fitness and his virtuous gym attendance:

*Vic: Dr Brown at our doctors....reckons that I am probably the fittest person on their books of my age....I am marginally fitter now than I was before I had the, if you like the little scare...because I go to the cardio gym....but when I compare myself to an awful lot of other people....they haven't learnt by it and are not doing anything in comparison.*

These excerpts highlight the strong moral discourse about health promotion and self-regulation that makes sense of Smeeth and Hemingway's (2012) distaste for using tablets to '*mitigate against unhealthy lifestyles*'; this discourse presents a major obstacle to legitimating a decision to take statins, and helps legitimate a decision to decline them, as indicated by several of those interviewees who are not taking statins. Almost all those who are taking statins work within their interviews to circumvent this obstacle so as to present an acceptable identity, emphasising their virtuous adoption of healthy behaviours (alongside their need to take statins and other pills) and thus distinguishing themselves from other people who are lazy pill-takers. With statins, as with medication in general, 'need' serves to legitimate pill-taking, whereas choosing to take pills is something almost nobody describes themselves as doing: Geoff is the only interviewee who explicitly presents virtuous health behaviours as an option which he has rejected, instead opting for statins, which he describes as '*a light punishment for the sin of living badly*'. Unsurprisingly, few other interviewees present themselves as sinners.

## Discussion

These findings describe the moral discourses used to legitimate taking medication in general and statins in particular. In foregrounding the way tensions between such discourses are negotiated, this article builds on Dew et al's (2015) discussion of the moral discourses which inform the relationship between pharmaceuticals and identity and hence shape medication practices. However, examining how people come to take (or to decline) statins requires a further analytic move, situating these medication practices within a broader web of health practices informed by the widely-shared perception that statins are taken 'to mitigate against unhealthy lifestyles'. Because of this perception, statin-takers have to defend themselves against two threats to a presentable identity: they stand tacitly accused not only of 'being pill-takers' but also of having 'unhealthy lifestyles'.

Both these accusations imply a choice to take statins, so it is unsurprising that having 'no choice' is a particularly salient feature in statin-takers' accounts in these data. Describing some of the clashes of norms negotiated by people considering aspirin, Eborall and Will (2011) highlight the way 'need' confers legitimacy on pill-taking. In these data, too, those who take pills emphasise that they need them; 'a pill-taker' is someone who takes more pills than they 'really need'. Participants present 'need' as a binary quality, the antithesis of 'choice': almost nobody describes themselves as choosing to take pills, and several people state explicitly that they have no choice but to take them. This finding, that absence of choice is used to legitimate medication decisions, may help explain the low uptake reported by Will and Weiner (2015) in their study of over-the-counter statins. One plausible explanation of their finding that statins 'don't sell' is that choosing to go and buy pills for oneself, as opposed to obeying doctors' orders, threatens one of the main defences participants use against the 'pill-taker' accusation: one 'needs' pills if a doctor says so. This defence often articulates with 'having a condition', a status (discussed by Polak (2016)) whose circular relationship with 'needing medication' is implicit throughout these data.

Yet while 'need' is a necessary constituent of legitimacy, it is not a sufficient one; some 'conditions' are not morally neutral, for two reasons: either the elevation of a problem

to 'condition' status may be contested, or the condition may be of a kind that one ought to have avoided getting. Pain is an example of a problem whose legitimation of pill-taking is fragile – in these interviews, only other people take pills for 'a little niggle'. Another example of fragile legitimacy concerns insomnia; Gabe et al (2016) describe the morally-charged negotiations involved in talk about sleeping pills. Like in the data here, Gabe and colleagues found 'need' was constituted either by having problems which functioned as a condition (in participants they classify as 'deserving' pill-takers), or by 'compliance' with medical advice. This need was invoked to legitimate pill-taking, and balanced against concerns about side-effects or addiction. In a group Gabe et al call 'sinful' pill-users, however, the fragility of insomnia as a legitimating condition is highlighted: without medical advice, its status falls below the threshold for legitimation, rendering pill-taking 'naughty'.

The threat to identity against which our participants defend themselves is different: those taking pills state unequivocally that they 'really need' them. The weakness in the legitimating process is not in the framing of cholesterol and heart problems as conditions, but in the stigma attached to these particular conditions. Crawford's (1994) reflections on the cultural meanings of AIDS help to understand this stigma. Although heart disease is not infectious, it shares with AIDS the moral opprobrium derived from perceptions about lack of 'self-control'; elsewhere (1980) Crawford describes this as a component of healthism: 'failure to maintain health is ascribed to ...a failure of will'. The number of health problems liable to incur such blame is increasing as more are recognised as potentially 'caused by lifestyle factors'; hence heart disease and statins constitute a useful case study, a context in which the anti-pill trope informs a preference for declining medication in favour of using will-power to make health-maintaining 'lifestyle choices'.

The health promotion discourse this reflects is surfaced here by participants' frequent references to knowledge about cholesterol, diet and exercise, and by their morally-coloured accounts of health practices. This discourse incorporates widespread knowledge linking coronary candidacy to '*unhealthy lifestyles*' (Angus et al, 2005; Davison et al, 1991; Weiner, 2009), together with values concerning individual responsibility and autonomy. Having this knowledge (enough but not too much) is a

constituent of constructing oneself as a responsible citizen, and as one has the autonomy to act upon it, it follows that someone needing statins is particularly likely to be accused of being ignorant, lazy or irresponsible. Autonomy can be seen as the obverse of dependency (on medical advice, for instance), but this binary framing fails to represent the complex calibration process seen in participants' accounts of their health practices, where they work to resolve a tension between stubborn rejection and passive acceptance of doctors' advice. This work exemplifies the wider enterprise of which it is a constituent, the enterprise of handling two rival tropes that inform medication practices, one framing 'a pill for every ill' as desirable medical progress while the other frames it as undesirable medicalisation. Rather than amalgamating competing tropes or balancing them against one another, this calibration work serves to 'allow people to move between different kinds of talk relatively smoothly', as Will and Weiner (2014) describe in the context of talk about 'healthy living'. Medication practices are thus informed and legitimated by a multiplicity of discourses, rather than a single unified one.

As well as informing participants' accounts, these multiple discourses are also visible in research and commentary about medication-taking, blurring the boundary between stances traditionally associated with either the biomedical or the social science community. In the biomedical literature, growing interest in 'overdiagnosis' or 'too much medicine' (Moynihan, 2012) in recent years shows that an anti-medicalisation discourse is gaining ground; patient empowerment and choice are unquestioned goals in health policies and clinical training; and Smeeth and Hemingway's (2012) comment voices an increasingly prevalent anti-pharmaceuticalisation trope. Within the social science literature, this trope is sometimes implicitly in tension with a broader anti-medicalisation discourse that highlights the medicalising effect of individual responsabilisation for health and identifies healthism as 'a form of medicalisation' (Crawford, 1980). The case of statins is used here to problematise that tension, highlighting the articulation between critiques of 'dependency' on doctors and pills (Crimson et al, 2007) and the growing valorisation of the autonomous, self-determining individual characterised by Crawford (1994) as a 'bourgeois ideal'. This study suggests

that those offered statins negotiate a complex tangle of conflicting norms which is perhaps too seldom considered by those who advise or study them.

### **Conclusion**

Pill-taking can be an obstacle to presenting an acceptable identity. To legitimate taking medication, people present themselves as taking pills because they need them; it would be irresponsible or stupid not to take pills one needs. Needing statins, however, constitutes an extra threat to the enactment of moral adequacy, because of the well-recognised health promotion discourse which suggests that a healthy lifestyle can reduce cholesterol or prevent heart problems. Those who reject statins invoke this discourse. More surprisingly, statin-takers indicate acceptance of it, too; most emphasise that they need statins despite their own virtuous lifestyle, rather than through choice. Their accounts reference both possible framings of 'a pill for every ill': by emphasising that pills '*keep us alive*' one avoids presenting oneself as '*a pill-taker*'.

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## Discussion

There is a considerable body of sociological literature on the way medical decisions and practices are shaped by concerns about identity and moral adequacy. Within that literature, several authors [Adams, Pill and Jones, 1997; Murdoch et al, 2013; Pound et al 2005] highlight the way taking medication may damage identity by rendering illness visible. These authors particularly emphasise concerns that pill-takers and inhaler-users indicate about the visibility of illness to other people. Murdoch et al draw on Goffman's concept of performance [1959, in Murdoch et al, 2013] to cast presentation and 'image management' as central constituents of the work of living with chronic illness, a framing emphasised within the methodological approach used in this thesis. As well as supporting these accounts, the findings presented here also build on them: the paper argues that in addition to a potential for stigmatisation mediated by illness visibility, the practice of taking medication constitutes a direct obstacle in itself to presenting an acceptable identity. The data are used to demonstrate that rebutting the unwanted 'pill-taker' label while talking about taking lots of pills requires complicated identity work. Central to this rebuttal is the distinction participants make between themselves and people who they describe as taking too many pills. Taking too many pills is implicitly construed as taking pills one does not really need; nobody identifies themselves in this way, and several interviewees visibly work to show that they take fewer pills than other people they know, or that although they take lots, they *'really really need them'*. Thus necessity is used as a key defence against the threat to moral adequacy constituted by 'being a pill-taker'.

In the particular case of statins, this identity work has to overcome an additional challenge: although needing statins is an effective way of defending one's moral adequacy against the accusation of being a pill-taker, it lays one open to a different attack, because statins are widely framed in these data as something one ought not to need. The paper draws parallels between statins and other kinds of medication which have been described as particularly tricky to legitimate, such as sleeping pills, citing study data in which participants reference the widespread health promotion discourse constituted by knowledge about coronary candidacy and acceptance of individual responsibility for maintaining health. This discourse casts statins as an alternative to 'a healthy lifestyle'; in one participant's words, taking statins is *'a lazy option'*. This

framing is particularly often visible in the accounts of participants who have decided not to take statins, their references to eating lots of fruit and taking lots of exercise contributing to their self-presentation as people who have made ‘virtuous lifestyle choices’ which are sometimes explicitly cast as *‘instead of taking....medication’*. Perhaps more surprisingly, many of those who are taking statins reference the same framing, emphasising that, as well as taking the pills, they too adopt ‘virtuous’ behaviours. For instance, some of those who are taking statins lay particular stress on the large amount of exercise they take, sometimes coupling this emphasis with descriptions of themselves as very fit. In their approving tone, such descriptions surface not only the specific discourse that underpins heart-focused health promotion but also the general discourse of healthism, with its elevation of health to ‘a super-value’ [Crawford 1980 p379]; the paper portrays the way these discourses combine to shape identity work in relation to statins.

An example from the data helps to clarify these points, both the established one that pill-taking can harm identity by making illness visible, and the two new points made in the paper: first, that the practice of regular pill-taking inherently threatens the presentation of moral adequacy, and second, that needing (and therefore taking) statins constitutes a special extra threat to this presentation. Peter, a participant who now takes statins and other regular medication following his heart attack, reports a conversation with his friend Fred just before the attack: *‘he was telling me how many tablets he took and his wife took ... and I was saying, I am sorry to hear all this, as my wife and I are fully healthy.... That was what I said ... “Fred, I haven’t taken a tablet for years, sorry to hear you are so unhealthy”’*. As well as illustrating that taking lots of tablets can serve as a marker for ill health, the tone of Peter’s remembered statement is one of pride about being *‘fully healthy’*. This pride, contrasted with pity for Fred, supports a central feature of Crawford’s account [1980] of ‘healthism’: assessments of health are inherently value laden. In addition to his state of health, Peter’s account suggests that not taking any tablets for years is cast as a positive attribute, a source of pride in itself; this complements many other instances in the data where participants emphasise that they are not ‘pill-takers’.

Elsewhere in his interview, Peter is one of several people taking statins after a heart attack who talk in detail about their virtuous health behaviours. He links these to his annoyance at having a heart attack that was implicitly unfair; this impression is

reinforced by the way he subsequently uses a lengthy description of his many virtuous health behaviours to present his heart attack as not just unexpected but undeserved: *'we were eating lots of fruit and ... vegetables and, all those things you are supposed to do for a healthy lifestyle...so when I had a heart attack I was really annoyed'*. Along with other examples cited in the paper, these excerpts illustrate that legitimating statin-taking is particularly challenging; needing the pills is not enough, because one ought not to have needed them. Having a cardiovascular disease is a threat to identity because of the 'common knowledge' that links such diseases to an individual's failure to do *'all those things you are supposed to do'*.

As well as building on research about the relationship between pill-taking and identity, this chapter makes a further contribution to the literature about decision-making and medication practices. The papers in chapters 3 and 4 identify the paucity within the data of any indications of a recognisable 'choosing' process, characterised in the decision-making literature as involving deliberation and a weighing of benefits against costs [Elwyn & Miron-Schatz, 2010]. The paper in this chapter explains that paucity: it shows why people who take regular medication work hard to present themselves as needing to take their pills, and then often present this as the obverse of choosing to take them. Choosing to take pills – in one participant's words, *'affecting'* to take them – identifies one as a pill-taker, an unwanted label that is warded off by needing pills; unsurprisingly, then, choice is often explicitly rejected as a description of the way a participant has come to take statins. So this chapter complicates the widely accepted model of deciding as a cognitive process centred on choice, and informs a move towards the new model outlined in Chapter 6, where deciding is portrayed as a social practice involving both multiple interactions and the discursive framings that make sense of these interactions. For the overall story told in the thesis, the chapter marks a significant shift of direction, a broadening of the object of study from 'the way people decide about statins' to 'the way people come to take (or to decline to take) statins'. It is this question of how people come to take statins that is explored in the next and final Findings chapter.

## Chapter 6: Situating decision making within a web of everyday practices

*Geoff: 'It's now become so commonplace...and that ... helps one live with the idea that it's the right thing to do.'*

### Introduction

To outline the contribution of this final Findings chapter, a good starting point is the clinical puzzle which prompted the study reported in the thesis: despite clinicians' efforts to engage patients in a shared decision making process informed by evidence-based guidelines, many people who the guidelines suggest would gain significant net benefit from taking statins end up not taking them. At the beginning of the research process it was hoped that this puzzle could be solved by answering the question 'How do people decide about statins?' This question was informed by the assumption that 'deciding' could most helpfully be understood using the standard model that underpins research and practice about shared decision making, framing it as a cognitive process constituted by deliberation, weighing up options and choosing what to do [Elwyn & Miron-Schatz, 2010].

Through the iterative process of research conducted over several years, every element of this simple starting point was problematised and broadened. The initial focus on how people decide not to take statins was challenged early on; interviews with people who had been offered statins generated useful data from participants who were taking them as well as data from participants who were not. Analysing and comparing data about these two groups of people shed light on some interesting differences between them. In particular, many of those who were not taking statins indicated that they had deliberated about it, and referenced uncertainty about needing them, sometimes specifying that this uncertainty was the reason why they had decided to decline the statins; in contrast, there was almost no indication of deliberation or uncertainty in data from people who were taking statins, and some stated explicitly that they had no choice but to take them. To have ignored this asymmetry and stuck with my initial focus on people who do not take their statins would have wasted a lot of analytic potential, and risked ending up with an unsatisfactorily truncated story. So I extended the focus of data generation and analysis, to enable me to construct a story that accounts not only for people deciding not to take

statins but also for the way many people do end up taking regular preventive medication for long periods.

These findings about uncertainty and necessity have been presented and discussed in the last three chapters; they cast doubt on the usefulness of conceptualising ‘deciding’ as a process in which one balances advantages against disadvantages and makes a choice, doubts which are examined and discussed further in the paper in this chapter. The question addressed here is ‘How do people come to take (or not to take) statins?’, a question which subsumes ‘How do people decide?’ rather than replacing it. Once the object of study was broadened in this way, it became necessary to account for a large body of data concerning the everyday sociomaterial practices through which regular pill-taking is enacted, data which might have been left unused or relegated to the periphery of a study narrowly focused on the cognitive process of decision making.

Examining these everyday practices, and considering the ways in which they involve work that is shared with significant others and entangled with everyday household routines, helped to foreground the articulations between ‘deciding’ and ‘doing’. To account for these complex articulations and entanglements, and in particular to account for the way people do come to take regular medication, the paper below proposes a new model of decision-making, casting it as a social practice that is inseparable from a web of household medication practices with both discursive and material elements. The paper draws on data about material practices and also on data about the work participants do within their interviews so as to present themselves as doing ‘the right thing’. These data inform an account of the way everyday medication practices may contribute to knowing one is doing the right thing. This account is used to underpin the proposal that, at least in the context of interventions like statins (interventions that require the patient to do something herself, every day for years, in her own home), deciding to do something is best understood as constructing a presentable account of doing it, a story which one is happy to present to oneself and others. In the context of changes in physical activity, Nettleton and Green [2014] describe such a story as ‘thinkable’, an attribute rooted in tacit practical knowledge; they emphasise the cogency of such knowledge in determining whether or not a course of action gets adopted. This tacit practical knowledge is gained through everyday experiences, actions and interactions; data about these practices are used to construct the argument in this paper.

## **Paper 5: Taking longterm medication: deciding and doing**

*(This paper has not yet been submitted for publication)*

## **Abstract**

In this qualitative study we explore how people come to take statins and other longterm medication. Using data from interviews with participants who had been offered statins, we looked for references to the two key constituents of a deciding process specified in accounts of shared decision-making: deliberation, and the weighing of the medication's advantages against its disadvantages. In striking contrast with reports of other empirical studies, weighing or balancing was almost never indicated in the data presented here. Additionally, there was a marked asymmetry between participants who were taking statins and participants who were not; deliberation was a prominent feature of accounts of deciding not to take statins, whereas it was very seldom visible within accounts of taking them. People taking statins often emphasised that they had no choice about it, while those who were not taking statins used "*you have to think about it*" to account for not doing it. Rather than simply taking the accounts of people who were taking statins to indicate that an offstage decision was informing their everyday pill-taking, we examine the complex articulations between decision-making and everyday medication practices, and propose a new model of what decision-making looks like. In this model, deciding to act in a certain way means constructing a story that one is comfortable presenting to oneself and others; acting in that way is "*the right thing to do*", "*an idea that one can live with*". Thus decision-making is cast as a collection of social practices that includes gathering information and using it to build knowledge which informs a presentable story. This shift to a practice-centred account situates decision-making as inextricably entangled within a web of household routines and practices. We highlight the reciprocal relation between the knowledge that informs the enactment of daily pill-taking, and the web of sociomaterial practices which contributes to knowing medication-taking is the right thing to do by helping frame it as ordinary and "thinkable", a web within which responsabilising discourses constitute an integral element. As well as helping to understand how people come to take longterm medication, this model leads to shifts of emphasis applicable to a wider range of health practices: cognitive work and doctor-patient interactions remain visible but are moved out of the limelight; patient autonomy is of interest only insofar as it contributes to



agency, which is presented as inherently relational rather than individual; and health literacy is cast as just one constituent of the everyday health competence required to take care of oneself.

## **Introduction**

Taking regular longterm medication is an increasingly common thing to do, as more people reach an age at which they are likely to be diagnosed as having a non-communicable disease or chronic illness, or as being at high risk of developing one, while biomedicine offers an increasing range of interventions to address these conditions. So it is important to understand how longterm medication-taking is done. Two bodies of research seek to further this understanding: one focuses on medication decision-making and the other on medication practices. These two bodies are largely separate; the article bridges the gap between them, emphasising the complex articulation between “deciding” and “doing”. Drawing on qualitative data from interviews with people who have been offered statins, we identify problems with the model used in the extensive literature about decision-making. We present an alternative model of “deciding” to address these problems, a model that helps us build a plausible and empirically-grounded story about the way people come to take statins, as well as shedding light on the way others decide not to take them.

Deciding is generally defined as a cognitive process. Writing about what constitutes “a good decision”, Elwyn and Miron-Schatz [2009] describe its key process as “deliberation... [followed by] choosing an option”. This process of thoughtful choice is recognisable in accounts of empirical research; Pound et al [2005] synthesise qualitative evidence that people “weigh up the benefits of taking [medication] against the costs of doing so”, while Benson and Britten [2002] report that participants in a study of people taking blood pressure pills “balance reservations against reasons for taking [their medication]”. Benson and Britten situate their article within the literature about shared decision-making, concluding that their findings will help doctors “reach concordant decisions” with their patients, the central goal of shared decision-making [Elwyn et al, 2003]. In their account of the evolution and key features of shared decision-making, Charles and Gafni [1997] point out that the deciding process will

differ in different contexts, and they identify two salient dimensions of this difference: the urgency with which medical intervention is needed, and hence the speed of decision-making required; and the existence of different options considered reasonable by doctors. These two dimensions are identified by Edwards et al [2005] in data from focus groups where doctors talked about the circumstances in which they would promote shared decision-making: the authors report that the doctors studied regarded patient involvement in treatment decisions as feasible only when there was time to promote it (although the main constraint on time here was not medical urgency but pressure of work), and appropriate only where there was “clinical equipoise” between available options.

Using these two dimensions, deciding about longterm preventive medication such as statins seems a context where the shared decision-making model would be readily applicable. However, authors such as Charles and Gafni [1997] and Montori et al [2006] point to the need to modify this model in order to use it to describe decisions about problems that do not require very urgent treatment, rather than assuming that a model that is helpful for understanding decisions about a surgical operation, for example, will be equally helpful in relation to decisions about longterm treatments like statins. Unlike an operation, using statins requires the patient to take an active part in enacting the intervention, in their own home, every day for years. Considering decisions about interventions of this kind, both Charles and Gafni’s and Montori et al’s papers highlight the involvement of people outside the doctor: patient dyad, both other healthcare professionals and the patient’s friends and relatives, and emphasise that deciding takes place in a series of different clinical encounters. This distributed decision-making model is extended by Rapley [2008] to incorporate interactions in non-clinical settings and recognise the contribution of technologies such as websites and television. Building on Rapley’s account, Edwards et al [2013] draw on qualitative data from a study of health literacy in people with a variety of “long-term health conditions” to describe the way family and social networks “passed on their health literacy skills”, thus co-producing “distributed health literacy”. Edwards et al’s account illustrates the relationship between debates focused on decision-making and debates focused on health literacy, a relationship that has become closer as the remit of health

literacy has expanded: rather than simply concerning “health-related tasks that require reading and numerical skills”, Edwards et al describe it as “a resource for managing one’s health... and making health decisions”.

By portraying decision-making as distributed across multiple times and places and involving interactions with things as well as with multiple people, these models do make a salient move to broaden the conception of deciding in a way that seems helpful for understanding how people decide about medical interventions that are themselves distributed, like longterm medication. In respect of what actually constitutes deciding, however, distributed decision-making remains identical to deciding that is done during a single binary encounter: both these kinds of deciding are presented as cognitive processes. For instance, Edwards et al [2013] specify that the concept of health literacy centres on the ability to perform “tasks such as information-seeking, decision-making, problem-solving, [and] critical thinking”; it is this ability that is produced in their participants with help from “health literacy mediators” amongst their friends and family. Contrasting distributed decision-making with conventional models, Rapley describes each episode of deciding as “another-decision-in-a-series”, but his heuristic, “distributed cognitions”, emphasises that the role of all the multiple interactions he describes is to collect information that is used in making up one’s mind. This purely-cognitive model implies a clear separation between deciding about pill-taking and enacting pill-taking, connecting the two only insofar as the action is assumed to be informed by the decision, with decision preceding action in a tidy sequence of events.

A complete separation between making up one’s mind and acting upon one’s decision underpins the literature about an extensively-discussed phenomenon: people often do not take prescribed medication. This phenomenon is reported particularly frequently in connection with longterm medication; in two studies of older people advised to take statins (Jackevius et al [2002], Benner et al [2002]), for instance, fewer than half were still doing so after two years. Within the biomedical community this “non-adherence” is widely identified as “a common and costly problem” [Marcum 2013], and much research attempts to explain and solve it, focusing on ways to overcome obstacles to adherence which are often classified as either intentional or non-intentional [de

Simoni et al 2015]. This typology of obstacles maps neatly onto a clear distinction between decision-making and the practical business of taking pills, and focuses only on people who do not take their medication. Such accounts of non-adherence are complemented by a body of qualitative research that re-frames what these people are doing as “rejecting” or “resisting” medication [Dowell and Hudson, 1997; Pound et al, 2005]. These qualitative accounts do consider people who take their medication regularly (“accepters”) as well as people who do not, but the focus on deciding as distinct from doing remains clear, with material medication practices mentioned only as something “active accepters” may decide to modify so as “to make the regimen more acceptable”.

The research presented here examines “the regimen” itself and explores the way people do come to take regular medication. In this respect it builds on accounts of medication practices [Dew et al 2014] and of the shared work of living with chronic illness [Corbin & Strauss 1985, Pickard and Rogers 2012]. These accounts, like accounts of distributed decision-making, describe an expanded spatialisation in both space and time, with the home (rather than a clinical setting) as the place where most of the work gets done, and they emphasise that this work is collaborative, involving household members, friends and acquaintances as well as a range of health professionals. Instead of focusing on decision-making, however, accounts of household practices and shared work identify more complex interactions with medical advice, describing how it gets modified by being combined with other knowledge and norms, rather than simply getting accepted or rejected. This approach, setting out to portray the untidy web of sociomaterial practices that produce daily pill-taking, is the one we adopt here in preference to approaches conceptualising decision-making as a cognitive task producing the intention to act, an intention that is then acted upon as far as “non-intentional barriers to adherence” allow. To present an alternative to this tidy binary picture, we build on a detailed examination of the two-way connections between deciding about medication-taking and actually doing it, exploring the way decision-making is constituted and enacted and proposing a model of “deciding” that explains how people come to take longterm medication such as statins.

## **Methods**

This was a qualitative study that generated data by interviewing people aged between 53 and 87 who had been offered statins. Of the thirty-four participants, nineteen said they were taking statins; this paper draws principally on their accounts, while making use of some comparisons with data from people who were not taking statins.

Participants were recruited in community settings in East Anglia between 2011 and 2013, and interviewed face-to-face, twenty-two with their partner and twelve individually. The author[s] conducted all interviews, which were recorded and transcribed verbatim. Ethical approval was obtained from [author(s)' institution] before data collection began. All names in this paper are pseudonyms, and identifying material has been removed.

Interviews were semi-structured, covering participants' everyday medication practices; their health-related knowledge and where this came from; and their decisions about medication. Thus, although participants knew the study centred on "deciding about statins", the topic guide sought to facilitate talk about a wide range of health practices.

Almost all interviews took place in participants' homes, and this provided the opportunity to observe some material practices and technologies related to pill-taking. In the couple interviews, it was also possible to observe elements of the shared work of knowledge construction that underpins decision-making, and the co-construction of accounts of participants' decisions and actions. As discussed by Polak and Green[2016], joint interviews can provide analytic purchase compared to individual interviews, acting as a hybrid between observation and interviewing and also combining some of the advantages of individual interviews with those of focus groups. For example, interviewing a couple may strengthen inferences about what people do from what they say they do, particularly where the two interviewees correct or contradict one another.

Analysis used elements of the constant comparative method and was informed by discussion with colleagues, generating an empirically-grounded account of the multiple interactions involved in taking regular medication and the discourses that inform these interactions, and of the way "deciding to take statins" articulates with these

interactions and discourses. As Radley and Billig [1996] advocate, data were framed as accounts produced within the interview setting, shaped by participants' need to generate a story they are comfortable presenting. Data were thus taken not as a representation of beliefs or views, but as a source of clues about the discourses that make some stories more presentable than others, an approach modelled, for example, in Green et al's [2003] use of talk about food practices to study the "rules of thumb" governing participants' choices. This methodological approach circumvents the difficulty of using interview data to build robust inferences about how people make up their minds, inferences that rest on the assumption that what people say provides a valid picture of what they think. Instead, our aim here is to construct a plausible account of the often-tacit discourses that make taking (or not taking) statins something that interviewees are comfortable to present themselves as doing.

### **Findings**

These findings situate decision-making in relation to a complex web of practices that produces pill-taking, highlighting the way a decision both informs everyday routines and is underpinned by them. The first section identifies the need to look for an alternative to the portrayal of deciding as a cognitive, choosing process in which reasons to take medication are balanced against reasons not to. The alternative account which follows frames decision-making as a key constituent of the collaborative work of looking after oneself, inextricably entangled with the social and material practices involved in knowledge construction and in accomplishing regular pill-taking. This framing is used to explore first the way everyday medication practices shape deciding and then the way decisions shape medication practices.

### **Deciding: coming to know "the right thing to do"**

In view of the fact that deliberation is a key constituent of decision-making in the literature, it is visible strikingly seldom in data from interviews with people who say they are currently taking statins. This finding is highlighted by a comparison with accounts of deciding not to take statins, where deliberation is frequently visible; an excerpt from one such account sheds light on what is absent from statin-takers'

stories. Julie, who stopped taking statins recently, was interviewed with her husband David:

*Julie: I read in the paper that statins can contribute to breast cancer...well I've had breast cancer...so I didn't want it again...so I just came straight off them...so whether that was the right thing to do I don't know.... and then Saturday's paper said that statins can help hold off...strokes and that and I'm thinking different... the thing is it was the same paper that said about contributing to breast cancer*

*David: But medical opinions change monthly, don't they.*

As well as describing a deliberative process, Julie indicates some of the work of knowledge construction that supports it, work that involves acquiring and evaluating information in a series of interactions distributed over time, drawing on a variety of resources including David and the newspaper. In this respect, what Julie is doing closely resembles the first steps of a distributed decision-making process: assembling information about the advantages and drawbacks of two alternative possible courses of action, and using her personal values and preferences to assess them. As regards the way that the information gets used, however, Julie's account is a poor fit with the standard decision-making model; she is not weighing up the badness of breast cancer against the badness of a stroke, or the likelihood of causing breast cancer against the likelihood of preventing a stroke. Rather than enacting any practice recognisable as a weighing-up of benefits against harms, Julie is attempting to negotiate the tension between conflicting pieces of information in order to identify "*the right thing to do*". Her perplexity that "*the same paper*" has provided both these two pieces of information indicates that she sees the two as conflicting, rather than as two true facts to be balanced against one another. David supports her interpretation with his prompt explanation for the conflict: "*medical opinions change monthly*".

Julie's deliberation, leading to her not taking statins, exemplifies a finding common in these data: explaining their decision not to take statins, several participants say "*you have to think carefully about it*", and some, like Julie, offer detailed accounts of this thinking. In contrast, almost nobody who is taking statins gives any indication of deliberation when asked how they came to be taking them. Instead, they reply by

explaining why they need statins, referencing either a problem that needs treating, such as cholesterol or heart problems, or a doctor's seemingly unquestioned advice. 'Choosing' to take statins is only referenced within accounts that emphasise that the speaker had no choice about it because the medication was necessary. The way in which 'necessity' is constituted in the context of preventive medication, and the key role necessity plays in defending people who take pills against the accusation that they are 'pill-takers', have both been explored elsewhere [Polak, 2016; Polak, 2017]. Here, the focus broadens to examine the complex process through which people come to take statins; to build a clear picture of this process, data from interviews with people who are not taking statins are compared with data from people who are.

For instance, Julie's husband David takes statins since his heart attack, so comparisons can be made within their joint interview, both between the accounts they each give of their own decision regarding statins and between their contributions to conversation about each other's decision. When asked about taking statins himself, David's reply offers an interesting contrast with his sceptical comment about "*medical opinions*" when discussing Julie's dilemma:

*David: I was given a new lease, wasn't I? and they found things, so I've got to do what I'm told....I mean, if the doctor says I need then that's it*

Although he does provide justifications for his obedience – the "*new lease*", and the "*things*" wrong with him – David adopts a tone so emphatic that it seems to answer an unspoken challenge; his "*that's it*" indicates that taking statins is obviously the right thing for him to do and so needs no further discussion. A similar certainty is illustrated by the way another interviewee, Geoff, describes taking asthma medication: "*you've had asthma, that doesn't even really need to be talked about*".

The explanations in this data are produced by participants who have kindly agreed to help the interviewer by talking; the methodological task is to use their talk to explore how taking medication comes to be something that "*doesn't ... need to be talked about*", looking at the way knowledge and everyday routines combine to confer taken-for-granted status on the rightness of regular pill-taking. This exploration begins by



considering the processes of collecting information and using it to build usable knowledge about needing medication.

**Assessing wellness and using the assessment to inform health practices: an “everyday health competence”**

To know that one needs or does not need medication, one needs to know one’s state of health. The account presented here draws on two auto-ethnographies, Blaxter’s [2009] and Horlick-Jones [2011]. Horlick-Jones frames using the sensation of wellness to assess his state of health as an “everyday health competence”; he describes losing this competence after having cancer. Building both on this framing and on Blaxter’s account of incorporating her test results along with her bodily sensations to constitute what she describes as distributed embodiment, the data here are used to portray not a loss but an extension of everyday health competence. Participants competently assess their state of health by using not only their sensations, past and present, but also a collection of theoretical knowledge, both about their own body and about “medical conditions and treatments” in general. These different kinds of information are used to construct the knowledge that informs everyday medication practices.

***Gathering and ranking information***

To construct knowledge, people begin by gathering information; participants describe accomplishing this by means of interactions with multiple people and things. In their talk about reading, looking things up on the computer, watching TV and talking to people they know, these participants echo empirical findings presented by others in the context of distributed decision-making and health literacy [Charles and Gafni, 1997; Montori et al, 2006; Rapley, 2008; Edwards et al, 2013]. Several information-gathering technologies are visible during these interviews; participants show the interviewer a recent headline in the paper, or an information sheet from the hospital. Additionally, couple interviews allow observation of the way knowledge may be co-constructed within households, as illustrated by some of the data excerpts below.

A lot of information about statins is referenced in these data, information evidently held in common by most participants: everyone mentions cholesterol, several going on to talk about heart disease or about ‘healthy eating’; many indicate awareness that

statins “are not immediate-effect type of pills” intended to make them “feel any different”, and almost everyone mentions both side effects and the current widespread controversy about statins. The breadth of this range of information illustrates the extent to which “medical” information has e-scaped [Nettleton 2004] to become widely available, and the extent to which this kind of information gets incorporated within participants’ knowledge about heart disease in general, alongside experiential knowledge of their own or other people’s illnesses. In the following excerpt from Peter and Wendy’s interview, they visibly co-construct theoretical knowledge, presenting it as a shared possession:

*Peter: I have read that there is a product available in America which is claimed to clear the cholesterol out of your arteries.*

*Wendy: Clear the plaque*

*Peter: Clear the plaque out....but it, it takes the calcium out of your body altogether which is clearly not a good thing is it.*

*Wendy: No and you need that, don’t you.*

*Peter: Yes you do need a bit of calcium.*

Elsewhere in their interview, Peter and Wendy illustrate another feature that is very prevalent in these data: they describe a wide range of information-collecting strategies, include reading online and in magazines about heart disease and its treatments, and indicate that this is shared not only between the two of them but also with their son who is a paramedic. Several other participants mention that their children, friends or acquaintances are involved in the work of information-gathering, because, for example, their daughter “was the one that had the computer”. As well as building theoretical knowledge, interactions with other people are also a way of extending one’s individual practical knowledge; many people indicated knowing that a stroke is a terrible thing because, for example, their father had one and “it was horrendous to see the poor old boy”, while others talked about the reassuring effect of talking about their own sensations with others who had had heart attacks: “when I talk to anybody else, they have all got the same”.

Thus collecting information about health problems and their possible treatments is distributed, involving multiple interactions with people and technologies. This general information is complemented by both theoretical and experiential information about one's own body. Peter talks about information produced by a test his doctor did:

*I spent 25 minutes laying on [Dr X's] couch while he searched round with a - what's it called? – ultrasound, and ...after 25 minutes he said Mr Y, I have searched the whole of your heart and I can't find any muscle damage...So in fact my muscles had reacted badly to a blockage which I got a stent put in, and it hadn't actually, damaged the heart.*

As well as test processes in which he is passive, waiting for Dr X to tell him the results, Peter also describes collecting information about himself without Dr X's mediation, checking his own blood pressure and pulse for instance. He also cites bodily sensations which, he implies, shed light on his state of health, for example noting that he finds cycling up a hill harder than before and saying that he plans to mention this to his doctor. Apart from occasional hesitations in finding words like “*ultrasound*”, Peter references all these different kinds of information fluently; they combine to constitute his knowledge of his state of health, within an account that allows him to present himself as a competent person who knows how to take sensible care of himself.

Competence to assess one's health using an extended range of information involves making judgements between competing pieces of information; whereas Blaxter [2009] describes building her distributed embodiment by adding different kinds of information together, the data here often indicate tensions between one kind and another, particularly between test results and bodily sensations. Where participants negotiate these tensions or clashes, test results generally trump sensations, particularly in people who are taking statins. Amongst those people who have had heart attacks, several explicitly indicate a loss of confidence in sensations of wellness or illness, echoing Horlick-Jones' [2011] account, as Peter does here in response to a question about his current state of health:

*Peter: I think I am healthy...But then you see I thought I was healthy the day before I had the heart attack...so it is difficult to tell*

Later Peter tells a vivid and detailed story of the day he had his heart attack: he walked into the surgery up the road with what he thought was insignificant discomfort, but because of his ECG result he went straight on to hospital by ambulance. Thus, in this clash between sensations and test results, test results trumped feeling well. The opposite clash, between feeling ill and test results that suggest normal health, is also sometimes visible in these data, as it is in this excerpt where Debbie and Keith talk about having tests for his troublesome palpitations; they indicate no doubt that the test results (generated by a heart monitor and interpreted and communicated by a doctor) were correct, and therefore that Keith's feelings were misleading:

*Debbie: You thought you were getting these episodes a lot, for a lot longer than 3 seconds, didn't you?*

*Keith: Mm*

*Debbie: So the patient can't really tell what's happening....*

*Keith: It felt as though, you know often, quarter of an hour, 20 minutes um that that was happening, but when they actually looked at [the test result]... it wasn't at all.*

In contrast, some of those who are not taking statins indicate that for them, test results and related medical advice are trumped by feeling well; for instance, one participant who was prescribed statins but soon stopped taking them says '*Why dabble with something when you feel everything is ticking along nicely?*'.

Instead of considering knowledge as an object, a static, context-neutral pile of information, these findings suggest that it may be more helpful to consider the dynamic process of knowledge construction, framed here as a collection of sociomaterial practices. However, this framing leaves a key question unanswered, concerning the way knowledge is used once it has been constructed. To address this question it is necessary to take a close look at the role of knowledge in accounts of participants' medication decisions.

### ***Using information in accounting for decisions***

To look at the way people use information in these data, information about statin side effects provides a useful example, because almost every participant talks about them.

Most mention muscle pains, and many refer to the amount of conflicting information available. Yet the way different participants use this information varies widely. Patterns of difference are surfaced by comparing different groups of participants: statin-takers' talk about side effects differs from the talk of people who do not take statins, not in terms of the information content referenced but in terms of the role this information is given within accounts of medication decisions.

Several people who are not taking statins use side-effect information to explain their decision. For instance, replying to a question about why she stopped taking statins, one participant says *"I think it makes my osteoarthritis worse. I can't be certain but I think it does"*. No further explanation is offered; the implication is that it goes without saying that she should stop taking pills that make her arthritis worse. But people who are taking statins, too, mention unpleasant-sounding effects and ascribe them to statins. One such participant says that since starting them *"I get muscle wastage now, I've got all this skin it's all hanging"*, yet he gives no indication that he has considered stopping taking the statins: it goes without saying that continuing to take them is the right thing to do. Larry, quoted next, is another participant who knows he needs to keep taking statins; he reports that he has been told he must continue, following a heart attack that has left his heart damaged and vulnerable:

*Larry: I know there is you know a little bit of an uproar with statins, with regards to muscular pain and things. I have suffered a little bit of that but I couldn't honestly say it was down to the statin*

Here, Larry references a body of information about the controversy about statins, and implicitly evaluates the information that side effects are common as being less reliable than the competing information that they are rare: his dismissive reference to *"a little bit of an uproar"* suggests that this is uncalled-for, a fuss which tends to exaggerate both the severity of the side effects and the likelihood that they are *"down to"* statins in the first place. So far, this is a process of ranking one piece of information above another competing piece. He then uses the implicitly-reliable information as a yardstick against which to assess his embodied knowledge of *"muscular pain"*, presenting it as mild and only possibly caused by the medication.

The difference visible here between people who take and who do not take statins is thus not a difference in the information they reference; what differs is the role of this information in the story they present about what they are doing. In stories told by people who are not taking statins, particularly where people have tried them and then stopped, this information has a central role, although, as noted earlier, nobody in this study indicated that they had weighed up side effects against potential benefits of statins and decided to stop. In contrast, people who are still taking statins tell stories in which side effects are relegated to a small role at the periphery of accounts in which the rightness of taking statins largely goes with saying. This contrast suggests that whether or not someone takes statins is determined less by rational use of explicit knowledge than by often-tacit practical knowledge and discursive framings that determine *“the right thing to do”*. To understand how this practical knowledge is acquired it is helpful to examine the everyday material practices that help to make pill-taking an ordinary thing to do, and hence to make it a comfortable thing to present oneself as doing.

### **Everyday routines: making statin-taking “thinkable”**

The predominantly material practices that produce and support daily pill-taking have a key role in establishing its “ordinary” status. This can be seen in data about interactions both outside and inside participants’ homes, and in talk about medications in general as well as about statins in particular. In the next excerpt, for instance, Henry and his wife Liz are answering the interviewer’s question about how he remembers to get a supply of his various pills and take them regularly.

*Henry: I get the prescriptions from my local dispensary....and they remind you ... every bit of paper you get with your prescription they say your review is due on such a such a date*

*Interviewer: And actually taking them...?*

*Liz: He just has them with breakfast. We have a little pot on the breakfast tray, don’t we*

*Henry: A pot on the breakfast tray, that’s right*

*Interviewer: Yes, and the statins as well?*

*Henry: I take them at night... that is one of the things I have to remember to put out when I go to bed, but I do*

One feature of this excerpt is the way Liz and Henry present regular pill-taking as something successfully and easily accomplished. Such data are a poor basis for inferences about how hard it is to ensure a steady supply of long-term pills and to take them at the right time every day, or about how frequently Henry runs out of pills or forgets to take them on time. What can be inferred from these data, however, is that they help to present Liz and Henry as competent, sensible people who remember to “just” take their pills – very few participants describe frequently forgetting the pills that they say they need to take. Other salient features illustrated by Liz and Henry’s account include collaboration with people both within and outside the family, as well as the involvement of technologies such as the dispensary’s reminder slips and the pot of pills on the breakfast tray. Pill-taking is thus presented as an integral and unremarkable constituent of a collection of collaborative everyday practices, aligned with ordinary routine activities such as meals and bedtime. This entanglement within a broader web of everyday practices helps to establish the taken-for-granted status of pill-taking, making it seem ordinary.

Ordinariness is further strengthened by knowing that lots of other people like oneself take regular medication too, knowledge that is often surfaced in these data. For example Ann, one of the older participants, says:

*Ann: With some friends at a coffee morning...conversation got round to, as it does at this age, you know to all the pills and things that you take*

As well as the practice of pill-taking, specific kinds of medication are presented as reassuringly ordinary objects in themselves, something Eborall and Will [2011] describe in relation to aspirin. In these data, too, statins are presented as reassuringly ordinary by several participants who say they take them. Geoff is in his 50’s and often travels for work with a group of colleagues:

*Geoff: I have to remember to pack all my medication ...statins is one of the things I do need every day. And one [time] I forgot, and ... I asked around – did*

*any of my male colleagues of about my age and so forth, could anybody spare me a statin or two. And a couple of them said Yeah are you 20, 40 or 60? And it's now become so commonplace...and that also helps one live with the idea that it's the right thing to do.*

Unsurprisingly, older participants also indicate that taking statins is commonplace. Kathy attends a lunch club where the average age is over 70; she tells about the disappointing outcome of a raffle where grapefruit was one of the prizes:

*Kathy: Somebody had brought in a beautiful big tin of grapefruit...of course the lady that won it said I can't have this. She was going round all the club trying to get rid of it.... So a lady had it for her husband who wasn't on statins.*

As well as indicating that everyone at the club shares the information that you mustn't eat grapefruit if you are taking statins, this story shows that everyone knows everyone else is taking them. All having to turn down the raffle prize helps establish statin-taking as ordinary; there is no indication in Kathy's account that it is something embarrassing that anyone would want to keep secret. As Geoff says, knowing it is "so commonplace...helps one live with the idea that it's the right thing to do". This is tantamount to saying that its being commonplace helps Geoff and Kathy decide to take statins, if "deciding" to do something is seen as constructing a presentable account of doing it. So the final questions addressed here concern the discursive framings that make taking medication a presentable thing to do and shape the way it is enacted.

### **Relational agency and the responsabilising discourses which shape and constrain it**

So far, the findings presented contribute to an account of the way everyday practices influence decision-making. This account is one key constituent of a model that frames deciding as a social practice. To complete the model, two further constituents are examined here: the reciprocal way in which deciding informs the material routines through which regular pill-taking is accomplished, and the way normative discourses pervade the practice of deciding.



The articulation between deciding to do something and doing it is often elided from accounts of decision-making; the tacit assumption is that once one has decided to take medication, one just gets on and takes it. Where discursive constraints are discussed in these accounts, often within debates about patient autonomy and empowerment, they are cast as a feature of the relationship between a doctor and a patient. The findings here support those presented in Dew et al's discussions of household medication practices [2014] and the moral discourses that inform them [2015], shedding light on three features of regular pill-taking: it is a shared accomplishment; it involves multiple interactions within and outside the household; and it is shaped by tacit responsabilising discourses. Another excerpt from Julie and David's interview illustrates this. David takes statins, and although Julie has stopped taking them she still takes other regular longterm medication. She is unusual among these participants in volunteering that she sometimes forgets:

*Julie: I've got to remember, the times I've forgot to take them, it's a bit like oh god this is controlling my day....*

Instead of presenting the need to take pills as "*controlling [his] day*", David talks about the "*regimental*" control he exerts over his pill-taking; he presents this as a simple, single-handed accomplishment, but Julie's correction (and David's accepting laugh) highlights that this control is accomplished through interactions with her as well as the "*weekly box*":

*David: I've got a weekly box. I take aspirin and amlodipine in the morning, warfarin at 6 o'clock and the statin and the other blood pressure at 10 o'clock*

*Interviewer: Right*

*Julie: Mm*

*David: So I'm very into that pattern now, regimental ...I don't forget*

*Julie: No, but – I mean that's another thing about what I am saying about controlling you ... you mustn't forget to take them tablets, take them out with you when you go out in the evening...because he's got to take them.... as soon as you walk out the door I say have you got your tablets?*

*David: [laughs]*

In her statements that *“I’ve got to remember”*, *“you mustn’t forget to take them tablets”* and *“he’s got to take them”*, Julie reiterates her earlier framing of pill-taking as exerting control, both through its articulation with other everyday activities and through its role as something she has to remind David about.

David’s laugh suggests acknowledgement of this distribution of their shared work of looking after themselves, a distribution several other couples allude to. These are all heterosexual couples, and most but not all present the remembering and reminding as something the woman does, although several men say collecting a new supply of pills is their job: *“She doesn’t run out. I don’t let her run right out”*. Several interviewees who live alone describe similar sharing of work with others, not always family members. For example an elderly widow speaks of her reliance on a volunteer who runs errands including collecting her pills from the chemist. Other participants with limited mobility report that the pharmacy delivers regular supplies of pills, and many mention technologies that play a role in their pill-taking routine, such as blister packs which help to remind the participant what to take when. Susan shows the interviewer her spaceship-shaped timer device, alongside her husband’s blister packs:

*Susan: I’ve got this spaceship*

*Interviewer: Yes, do you prefer that to these blister things then?*

*Susan: Oh yes. Much easier. Cos it goes off, when there’s tablets to take....I’ve only got to turn it upside down, and they fall out in me hand.*

In another couple interview, Wendy describes reminding Peter about his pills, but her account indicates that she does more than simply remind him:

*Peter: I am not taking ramipril anymore. So I went and saw the pharmacist and said why aren’t I taking – sorry? [Wendy has interrupted]*

*Wendy: –clopidogrel, you still take ramipril...It was the clopidogrel you stopped taking.*

*Peter: Well something or other, I have lost it now.*

*[phone rings, Peter goes out to answer it]*

*Interviewer [female]: so sounds like, you're the one that runs all the pills, do you?*

*Wendy: [whispering] it's just easier to—cos you know what men are like... he takes the statin, because apparently they work better at night, that was what he was told, so before he has a drink, about three quarters of an hour before we go to bed, he will have that, just one, and then, he will have the ramipril and the aspirin first thing in the morning before he has a cup of tea , so, no I mean it's just easier, I just do that and, there isn't any sweat, by doing it, so I'm happy to do it, because at least I know he's had them.*

As well as providing another example of the way pill-taking is produced by collaborative work that dovetails with other everyday practices, Wendy's statement that "*there isn't any sweat, by doing it*" points to the underlying anxiety she avoids by making quite sure "*he's had them*", an anxiety which in turn points to her understanding that he must take his pills.

These excerpts illustrate two points. First, both the way in which "a decision" shapes everyday medication practices, and the way in which these practices are carried on, involve agency which is relational rather than individual. Second, the necessity of taking regular medication is a force which does not just legitimate medication-taking [Eborall and Will, 2011; Polak 2016] but also drives it. This necessity is the product of a deciding process that renders the practice of taking medication "*the right thing to do*", not only making it comfortable to present oneself as doing it but also making it uncomfortable to present oneself as not doing it. This is uncomfortableness is highlighted by the way Bert works to legitimate stopping statins, having been told he needed them after his heart attack:

*Bert: I felt terrible. I had headaches, um I couldn't sleep...I ached all over from head to foot...all day and all night. I stuck it for two months and then I, I rang Dr T up and she said "well pack them up"...I felt so – you know, I just couldn't, I couldn't put up with it*

Within this group of participants, Bert is unusual: he is not taking statins despite having had a heart attack and having been told statins were very important to prevent

another. He strongly emphasises the necessity of stopping taking them, both by describing extreme, intolerable side effects and by referring to his doctor's advice to stop the statins. Thus Bert is visibly constructing an account that he is comfortable presenting, in which he does not take statins; stopping taking statins is shown by his account to be "*the right thing to do*". The process of constructing that account constitutes "*deciding*". It produces a "*decision*" – an "*idea one can live with*" – and this idea informs Bert's daily medication practices, which include not taking statins.

Bert is like many other participants in explicitly referencing his doctor's advice. Such references are seldom central to accounts of medication practices in these data, yet the offstage voice of a doctor is often audible in accounts of needing medication. As well as an individual doctor's advice, these accounts implicitly reference a biomedical discourse in which managing to take necessary longterm medication contributes to presenting oneself (to oneself and others) as a responsible, competent person. This self-presentation work articulates closely with the work of deciding to take medication, particularly once "*deciding*" is framed as establishing that taking medication is "*the right thing to do*". The way both deciding and doing are informed by a responsabilising discourse, and the two-way relationship between them, is illustrated by the following account of managing a complicated medication regime:

*Hazel: Well when he came out of hospital it was all written down and we made a copy of that sheet... and we worked from that sheet –*

*Ted: – so there was no danger of, taking the wrong amount. Of course you do get into, the habit of, you know, one of these, two of those.*

Hazel and Ted have modified the technology supplied by the hospital, in this case by writing out the regime in a format that they found easier to follow; other participants showed the interviewer charts and timetables they had devised, larger and clearer than the hospital discharge information. Such modification achieves more than the pragmatic purpose of producing a legible instruction sheet; by creating their own sheet, Hazel and Ted enact their responsibility for accomplishing Ted's pill-taking. In talking about this they are presenting themselves as competent, sensible people, who are responding to the knowledge that he needs to take the pills in order to avoid the

*“danger of taking the wrong amount”*. Their account highlights that everyday pill-taking is the product of shared or relational agency, acting in a way which is informed by a tacitly responsabilising discourse; responsible patients take note of what the hospital has *“written down”*. No cognitive deciding process is visible in this interview; Ted’s only mention of how he came to start taking the medication is given in response to a direct question about this, when he replies with a vague comment that *“they put me on simvastatin”* but that he cannot remember when this was in relation to other events. To understand what is going on, it seems unhelpful to frame Ted and Hazels’ medication-taking simply as the product of an offstage, presumably cognitive decision-making process. Instead, the framing proposed here situates cognitive decision-making within a dynamic web of social practices and foregrounds the reciprocal connections between deciding and doing.

### **Discussion**

In the model of deciding implicit in the several literatures about it, the cognitive task of making up one’s mind about medication is distinct from the material tasks involved in enacting the decision to take pills regularly. In our alternative model this distinction is deliberately blurred; we highlight the complex articulations between deciding and doing, casting both as social practices and situating them within a web of everyday practices, a collection of routines and discourses through which people enact taking care of themselves and their significant others. This web has two key products relevant to longterm medication: a story about doing *“the right thing”*, which one is comfortable telling to oneself and others; and the group of material practices involved in taking a daily pill. In this model, “deciding” means producing a presentable story.

Between enacting pill-taking and constructing a story about it, there exists a two-way connection that is visible in the findings presented here: knowing that one is doing the right thing informs the work of enacting regular pill-taking, while the way pill-taking is made “ordinary” by its articulations with everyday routines helps to establish it as the right thing to do. In accounts of taking regular medication, participants work to present themselves as successfully managing two kinds of task: the cognitive tasks of establishing the rightness of taking medication in general and statins in particular, and

the material tasks through which taking daily medication is accomplished. Cognitive and material tasks are accorded equal salience in these data. The morally-infused cognitive work required to accommodate taking medication within an acceptable identity, and the special challenge presented by taking statins, has been discussed elsewhere in an account [Polak, 2017] that describes, for example, the complex process of calibration required to present oneself as sensibly heedful of doctors' advice without being blindly obedient to it. Regarding the material work of enacting pill-taking, indications of any difficulties are rare in the accounts of participants who say they take statins; successful enactment is central to participants' portrayal of themselves as competent and sensible. There is no indication that people perceive this portrayal of competence as threatened by acknowledging that carrying out daily medication practices is shared work, involving significant others as well as non-human technologies. For instance, couples like Hazel and Ted, rewriting the hospital's list for themselves, talk about this as their shared accomplishment, and Susan's relatively passive interaction with the "spaceship" pill dispenser is presented in her account as her own way of enacting regular pill-taking.

Cognitive and material elements, then, combine and articulate within the web of sociomaterial practices involved in producing regular pill-taking. A third essential constituent of this web is the collection of discourses that informs it, particularly the normative discourses that valorise "taking care of your own health". Some of these biomedically-rooted discourses are foregrounded by Dew et al [2015] in their discussion of pharmaceuticalised governance of household medication practices. Dew et al's account exemplifies a feature of studies that focus on the way medication gets taken at home: the deciding work done within clinical encounters is inevitably situated offstage, visible only via reports of what was said and done. Building on such accounts, we move away from models which frame deciding as a choosing process that involves balancing collections of implicitly context-neutral, stable information about competing options. Instead, our model brings deciding back onstage, characterising it as a discursively informed social practice and highlighting its two-way interactions with everyday medication practices. This character and these interactions are clearly visible

with regard to knowledge construction, one of the collections of practices that combine to constitute decision-making.

### ***Knowledge construction***

In the literatures about shared decision making and health literacy, deciding is widely portrayed as a process of using information; clinicians are enjoined to provide information to patients and help them to use it, tasks that are implicitly framed as value-neutral. Where values do get a mention, they are generally ascribed to patients: eliciting the patient's own ideas and concerns is a key element of standard recommendations about how clinicians or decision aids should facilitate informed shared decision-making, aiming to help the patient reach a decision concordant with their own values and preferences [Elwyn et al, 2003; Kurtz et al, 2003]. Accounts of distributed health literacy [Edwards et al 2013] or distributed decision-making [Rapley 2008] emphasise that these values and preferences are established in collaboration with significant others, a point supported by the findings presented here. Additionally, however, our findings underpin a detailed exploration of the process of knowledge construction required to move from acquiring a pile of information to making use of it, and highlight the way that every element of this process is inherently value-laden. We portray knowledge construction as a collection of sociomaterial practices: "arrays of activity" [Schatzki, 2001] within which normative discourses are an integral constituent [Rouse, 2001], shaping and making sense of what is said and done. This portrayal encompasses the cognitive tasks central to accounts of shared decision-making and health literacy, the material tasks involved in gathering information, the way both these kinds of task are undertaken in a distributed way, and the discourses that make sense of them. As well as generating a description of elements of the decision-making process widely elided elsewhere, this practice-based account specifically foregrounds the challenge of using a collection of often-conflicting information to decide what to do.

"What to do?" is the central question Mol [2002] describes her participants working to answer, in her ethnographic account of the way doctors collect and use a variety of different kinds of information to decide what to do about a patient's atherosclerosis. By emphasising the contingent nature of information, and the variability in its use in

varying contexts, our approach might seem to situate itself as incompatible with Mol's project: she sets out to engage with the "reality" of an illness rather than treating what people say as representing their perspectives on an un-knowable object. To this end she frames reality as multiple, enacted through a collection of different practices each of which produces a different real object called atherosclerosis, and contrasts this with the "perspectivalist" approaches she rejects. These real "objects-in-practice" are her objects of study, whereas ours are the practices themselves, and we disagree with her assertion that "it is possible to listen to people's stories as if they tell about events" [p20]; instead we frame interviewing itself as a social practice within which listening is one constituent. Yet there are useful similarities between our account and Mol's, particularly as regards her description of various ways in which doctors negotiate tensions and disparities between the information provided by different tests and by talking to and examining the patient. As well as being echoed by some of the findings presented above, Mol's description resembles Gabbay and le May's [2004] report of the way groups of doctors talk about using a collection of different kinds of information in deciding what to do; the authors helpfully bracket questions about the nature (real or constructed) of the problem their participants seek to solve, focusing on the distributed process through which they first gather a pile of pieces of information and then discard some pieces and combine others so as to construct "mindlines" that inform their actions.

Our account of knowledge construction incorporates two prominent features of Gabbay and le May's account: they emphasise the distributed, relational character of the process, contrasting this with models that assume that an individual doctor will take a piece of theoretical, "evidence-based" information and use it to inform their personal practice; and they foreground material practices, studying cognitive "mindlines" not only as objects of interest in their own right, but also in order to understand what gets done. This focus on actions supports the shift proposed here, focusing attention primarily not on autonomy but on agency. In the literatures on health decision-making and health literacy, autonomy is often a prominent topic of discussion, although the limitations of models centred on individual power are increasingly acknowledged. For instance Rapley [2008] uses the term "relational



autonomy” to describe the way interactions with other people help a patient to accomplish the cognitive task of decision-making; he highlights the limitations of understanding autonomy as an individual possession, citing data about a doctor-patient interaction in which the doctor emphasises that what he wants to know is what the patient thinks herself, not what her daughter says. The articulations between autonomy and agency, and between making a decision and acting upon it, are elided in Rapley’s account, where agency is mentioned only as “emerging” from a distributed process of knowledge construction; since deciding is the primary object of study, the connections between deciding and doing are not discussed.

In contrast, authors writing about self-care and the social interactions that support it [Pickard and Rogers, 2012], or about household medication practices [Dew et al, 2014], foreground material practices and situate knowledge construction as a means to an end, a way of coming to know what to do. These authors’ accounts have much in common with the one presented here regarding participants’ competence to build the knowledge that they need to inform their health practices. We suggest that this competence can be understood as an extension of Horlick-Jones’ [2011] “everyday health competence”, extending to include collecting information from a wide range of sources alongside feelings of wellness or illness, and also to include negotiating clashes between conflicting pieces of information so as to construct a usable body of knowledge. Alongside the highlighting of health competence rather than health literacy, a parallel shift of focus from relational autonomy to relational agency (a term proposed by Sarah Bernays [personal communication]), supports our framing of knowledge construction as one constituent of a web of health practices whose two key products are regular pill-taking and a presentable account of doing it.

### ***Decision-making: constructing a presentable account***

To be presentable, a story about health practices has to portray the tellers as sensible, competent people who are successfully looking after themselves and their significant others. In interview data, the story is being presented not just to the interviewer but to the interviewees themselves, enabling them to “*live with the idea that [what they are doing] is the right thing to do*”. Finding out that one has a condition that needs treatment, and becoming a person who takes regular medication, can be seen as a

biographical disruption (Bury, 1982). This applies particularly clearly to interviewees who describe a sudden frightening illness, the kind of event Bury writes about. However, a disruption of identity and embodiment is also visible in the accounts of those who were just told that they had “*got cholesterol*”, and advised to take statins; this similarity, and the circular, co-constitutive relationship between “*having a condition*” and “*needing medication*”, have been discussed elsewhere [Polak, 2016]. The biographical repair work such disruptions necessitate is cast by Corbin and Strauss [1985] as one of the three lines of work involved in managing chronic illness at home, and they emphasise that, as in our data, individuals share this work with their significant others.

In Corbin and Strauss’ account, biographical work concerns changes to the person’s plans for their life, and they discuss the reciprocal interaction between these changes and changes to the trajectory of the illness. Corbin and Strauss’s main focus is on material problems and practices, and so they do not specify what biographical work looks like, beyond a mention of a participant’s needing to “come to terms” with the disruption of his life plans; nor do they discuss the way that coming to terms with such disruption may be shared within a household, in the same way as the couples they study share material work. In this respect, Radley [1989] takes the exploration further in his discussion of findings from a study of men with heart disease and their wives; he uses “adjustment style” as a heuristic to focus attention on the ways in which people “cope with chronic illness”, and points out that adjustment “involves people in making sense of their situation, in giving meaning to ... experiences, and in legitimising their ways of coping in the eyes of other people”. Radley goes on to cast this “signification and justification... through communications...to others....not just [as] a commentary upon adjustment to illness” but as a key constituent of the process of accomplishing that adjustment, and he casts this process in turn as constitutive “of the kind of illness which those concerned believed coronary heart disease to be”.

Building on Radley’s framing, we offer a new model of “deciding about statins”: in this model decision-making is characterised as the process of constructing and presenting an account of a medical problem and its solution, and is situated at the centre of the web of everyday sociomaterial practices through which regular longterm pill-taking is

carried on. A collection of responsabilising discourses are an integral constituent of this web of medication practices; these discourses are surfaced in the data presented here, where participants' work to achieve what Radley terms justification. By emphasising the entanglement between decision-making and other discursive and material elements of the web of practices, we promote a move to replace the notion of autonomy, with its inherently cognitive character, focusing instead on competence and agency. Thus we frame our data as a collection of accounts through which participants present themselves as achieving agency through multiple interactions and relationships.

### **Conclusion**

Drawing on interviews with people who have been offered statins, we present data that are at odds with a model of deciding that centres on deliberation and choice. To account for these data we propose an alternative model, in which cognitive work is one element of a web of social practices whose two key products are deciding about medication and (if the decision is to take it) enacting regular pill-taking. Material practices within this web may support a decision to take medication by making it "thinkable" to do so. Knowledge construction is another element of the web; rather than collecting facts, weighing them up and using the balance to inform actions, we present a more complex account of the practices through which people build and use knowledge, highlighting the way discursive framings are integral to these practices and shape their products.

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## **Discussion: deciding as a social practice**

This paper offers a new model of decision making, arguing that the standard option-weighting model is inadequate to explain what is going on when people decide about longterm medication. The new model portrays deciding as a social practice, and describes a decision to take statins, for instance, as a presentable story that casts taking statins as the right thing to do. In the remainder of the chapter, I begin by offering an explanation for the discrepancy between my findings and empirical findings presented elsewhere about decision making, revisiting the analytic approach that led me to question the established model of decision making as a process whose key elements are deliberation and choice. I shall then move on to discuss some of the implications of moving away from this predominantly cognitive model to adopt a practice centred one.

### **Comparing different empirically grounded models of decision making**

The argument for a new model of decision making draws on findings that were unexpected in this study: setting out to examine ‘deciding’, I expected to find evidence of the kind of balancing process central to the widely accepted model in which people weigh up the advantages of an intervention against its disadvantages to choose the best course of action. The absence of such evidence is particularly surprising because other empirically grounded accounts, such as those by Benson and Britten [2002] and Pound et al [2005], do describe people as engaging in a balancing process. This discrepancy between other authors’ accounts and mine cannot be explained simply as an artefact of the methods I used to generate data: despite increasing doubt as to its helpfulness, discussed in Chapter 2, a question about ‘how you came to decide about statins’ was used in interviews throughout the research process. A likelier explanation for the difference between this and other accounts rests on a difference in the methodological assumptions used to analyse the data.

This explanation can be illustrated using an example that constitutes a deviant case within my data; the only clear indication in these data that a participant is balancing potential advantages against disadvantages of statins is given by Fiona, who does not take them. Early in the interview she describes being given a statin prescription by her doctor and throwing it away as soon as she got home, because she knew taking statins



would make it prohibitively expensive to get insurance for her foreign holidays. Later, in response to questions from the interviewer, she expands on this statement:

*Interviewer: When you got the prescription home, so you brought back the piece of paper, did you just throw it straight in the bin or did you look –*

*Fiona: – well I thought about it ... and then I just thought to myself well, no I won't bother with it, but, I must admit it was very bad of me because I didn't really look them up to see what they were, you know, what the advantages of taking them were, but it seems funny when you're sort of, weighing your life against an airline ticket, you know, the insurance for a holiday ...*

*Interviewer: ...was that really the major thing that made you put that prescription in the bin would you say?*

*Fiona: No the major thing was that if I take pills I don't feel well*

This could be construed as evidence that when she brought her prescription home, Fiona deliberated, considered the advantage (to '[her] life'), and then chose not to use it because of the two disadvantages she cites. But this reading overlooks the context in which she talks about these disadvantages: the concern about side effects, in particular, is mentioned only when the interviewer has in effect pressed her to provide a more sensible sounding reason for throwing away the prescription, after Fiona herself has presented the travel insurance as a frivolous reason. Rather than either of these reasons, it seems plausible that the central piece of data here is '*I just thought to myself well, no I won't bother with it*', taken alongside Fiona's later explanation for not taking statins while she does take longterm arthritis medication: '*with statins ... it's a preventive thing and you haven't seen any, any sort of need to take them*'. If one has not '*seen any... need*' to take medication, it goes without saying that one would '*just ...[not] bother with it*'.

These two alternative readings of the excerpt from Fiona's interview illustrate a possible explanation of the difference between my finding that participants do almost no visible weighing of pros and cons, and other authors' findings that suggest that this is what people do. What Fiona says can be framed either as a valid reflection of what she was thinking as she threw her prescription in the bin, or as post hoc rationalisations of her action, rationalisations prompted by direct questions which encouraged her to produce answers that would help her present herself as sensible and rational – without citing a

plausible rationale, she would have to present her action as irrational, misguided or stupid. Other authors may tacitly have adopted the first of these two possible framings; in so doing they may have fallen for what Nettleton and Green [2014] term ‘the seductive reading’ of such data as a list of stable perceptions and preferences that inform action. As discussed in Chapter 2, I question both this stability and the assumption that interviewees’ perceptions and preferences can robustly be inferred from what they say in interviews.

In this study it is particularly important to be reflexive about the weakness of assuming that what people say is simply an accurate representation of what they think or do about medication: these people all know that their interviewer is a GP, and so may try particularly hard to present themselves both as taking a rational decision and as succeeding in taking the regular medication they have decided to take. A similar caution is needed, however, regarding interviewing in general, as well as extending to other methods: the elaborate alternative data generation methods used by Dew et al [2014; 2015], for example, cannot circumvent the need for this reflexivity, both because participants still select the evidence they present, and because researchers still need to heed Bourdieu’s injunction [1990, p27] to acknowledge not only ‘the particular viewpoint that a ‘situated and dated’ observer takes up vis-à-vis the object’, but also the ‘much more fundamental alteration ... that is performed on practice by.... constituting it as an object (of observation and analysis)’. Casting what interviewees say as a context-specific performance, as I do in this thesis, does however allow credibly robust inferences to be drawn from the data about the discourses underpinning this performance, collections of knowledge and values that frame the interviewee as doing the right thing. These discourses are an integral constituent of the web of practices through which deciding about medication is enacted and regular pill-taking is carried on; the methodological decision to make them my primary object of study explains the difference between my conclusions about decision making and those of other researchers.

### **Deciding about statins: implications of a practice-based model**

Having presented an explanation for the difference between mine and other empirically grounded models of decision making, I turn now to examine some of the effects of this difference. The two kinds of model differ in the roles they accord to information and

choice, and in their implicit characterisation of power. Information acquisition, choosing between options, and autonomy all play central roles in the cognitively-based model implicit in writings about shared decision making and health literacy, writings that inform current health policies such as The Five Year Forward View [Stevens 2014]. In the paper above, to explain how people come to take regular medication, I propose to move the cognitive work of deciding away from centre stage and reposition it within a web of social practices. I reframe deliberation and choice as inessential constituents of this web of practices, casting information acquisition as just one element of knowledge construction and subsuming discussions of autonomy within discussions of agency. This move enables me to explore the articulations between deciding to take medication and taking it, articulations that other accounts either elide or else describe in terms of barriers that prevent people acting upon their intention to take the medication. Such accounts implicitly frame decision making and material work as neatly separated, connected by a one way arrow representing the power to do what one has decided to do.

This neat separation between deciding and doing makes sense within a discourse in which power is framed as a static commodity that is held by doctors or patients and sometimes shared between them or between patients and their significant others; the desirability of promoting autonomy is a prominent element in this discourse. To account for my data, however, I need to construct a detailed story about the interactions between deciding and doing, blurring and complicating the line that separates them. This story foregrounds relationships and interactions as the substrate of a web of practices, and reconceptualises power, understanding it as enacted within these relationships and interactions. The change this produces goes beyond introducing multiple interconnected arrows to replace the single, unidirectional one implicit in models of the way a cognitive ‘deciding’ process affects material action. The multiple arrows in my practice-based model exist only as characteristics of relationships and interactions, and so they have no stable context-neutral meaning or effect. In line with this dynamic, relationship-centred conception of power, I talk about agency here rather than about autonomy, signalling a shift of emphasis away from the ownership of power and towards the way power affects what gets done. This articulates with a parallel shift away from considering health activation and health literacy, both predominantly cognitive attributes that are said to ‘empower’ patients, conferring the potential for

action; instead I consider competence, an attribute that encompasses doing things as well as making up one's mind about them.

To illustrate the way these shifts are grounded in the data, some excerpts from Larry's interview are a good starting point. The first excerpt, describing how he came to do as he was told, could be taken as a good example of a doctor holding onto power and Larry backing down from an attempt to take some for himself. Larry recalls asking whether he really needed to take his tablets; he illustrates the following account of the reply by miming a wagging finger, clearly portraying the doctor as rebutting a perceived challenge to his authority:

*Larry: He pointed his finger at me and he said 'If you want to live a normal life you take the tablets and you'll live to be an old man ....Don't take the tablets and who knows what will happen'. So, I have always taken my tablets.*

But later in the interview a rather different picture emerges, one that suggests a more nuanced account of the way power is enacted in Larry's interactions with doctors, his own body and the material objects around him. Talking about current health problems that limit his activities, he visibly minimises the extent to which either the doctors or the effects of his illness have taken control of his life, framing the changes to his plans and his everyday routines as fairly insignificant. The healthist discourses that make sense of Larry's working to portray himself as still virtuously fit and active, playing down the effects of his cardiovascular disease, have been discussed in Chapter 5. Here, the same data are used as the basis for inferences about the relationships of power that shape his everyday routines and activities.

*'I was told to pack in work, because I did have a manual job, so I have stopped that, but I mean I was getting towards my end of doing that anyway, because I officially retire next June.... So, it just brought it 6 months earlier really '*

*'I can still go and cut the grass, I can still ride my bike, I can still and when I do feel fatigued I only need to stop for a couple of minutes, just to get my breath back '*

Larry's indirect reference to a particular offstage doctor or group of doctors who tells him 'to pack in work' typifies one of the ways in which doctors' instructions are

frequently indicated in these data; his account of obeying without making any significant concession of control illustrates the way many participants incorporate reports of such instructions into accounts of what they end up doing. As the paper demonstrates, such accounts centre on doing the right thing, and on needing (rather than choosing) to do it. This necessity, the 'it' that *'brought [Larry's retirement] 6 months earlier'* in the excerpt above, is something that participants come to know about by combining information from doctors with a mixture of theoretical and practical knowledge derived from a wide variety of other sources, to construct the knowledge that informs a presentable account of what to do.

In the paper above, I offer a detailed account of the social practices through which this knowledge construction is carried on, and contrast my account with others that frame decisions as informed by a pile of information, a framing that elides the distinction between information and knowledge. To describe the discursively informed work involved in negotiating clashes between conflicting pieces of information to produce knowledge about the right thing to do, the paper suggests using the concept of an extended health competence. This idea builds on Horlick-Jones' [2011] account of losing the competence to use sensory information to assess his own state of health confidently during an illness, and on Blaxter's description of experiencing an extension of her embodiment to incorporate test results. Lupton [2012; 2013], too, writes about the close relationship people establish with their test results, obtained by using mobile health tracking devices. This relationship is central to the paper and discussion in Chapter 4; here in Chapter 6, my focus broadens to examine the way people use a collection of different kinds of information, ranking competing pieces of information so as to discard one and use the other. As illustrated in the paper, the range of information participants reference attests to the extent to which 'medical' information has e-scaped [Nettleton 2004], coming to contribute to a growing body of publically accessible theoretical knowledge. For exploring the effects of adopting a practice-based model of decision making, what is interesting is the wide variation in the extent to which different participants reference theoretical knowledge or use it to account for their decisions.

This wide spectrum of variation applies both to the general knowledge about health problems or medical treatments that Nettleton writes about, and to theoretical knowledge about one's own body, the kind that may be incorporated into the extended competence needed to assess one's health and make medication decisions. Susan's joint

interview provides useful examples of the way theoretical knowledge is referenced and used at one end of this spectrum. For instance, she denies that she knows what her many pills do, giving no hint of discomfort despite responding to a question that might be heard as inviting a ‘Yes’ answer:

*Interviewer: Do you know what kinds they are?*

*Susan: I know one is for me diabetes, but the rest of them – No*

*Interviewer: And does that worry you at all?*

*Susan: Well, they should know what they’re giving me! [she laughs]*

At the opposite end of the spectrum, other participants cite large amounts of detailed information about what their pills do and why they need to take them; in the paper, Peter and Wendy talk about treatments that dissolve calcium deposits, while Don reports his cholesterol level to a decimal point and talks about ‘*watch[ing] the hard evidence of the blood test every 6 months*’, presenting this as his job to do. In contrast, Susan says ‘*I have me blood tests every day – my carer does it*’, and she points across the room to the book in which the results are written, on a shelf too high up for her to reach it for herself from her wheelchair.

In parallel to this spectrum of information use, the extent to which participants present themselves as actively accomplishing daily pill-taking varies widely. This variation, too, is illustrated in the paper. Susan is again at one end of the spectrum, talking about the pills ‘*they’re giving me*’ and showing the interviewer a pill dispenser that reminds her when it is time ‘*to turn it upside down [so that]... they fall out in me hand*’. In contrast, the paper cites data from Hazel and Ted’s interview that places them at the opposite end of the spectrum from Susan: they describe working together to use information the hospital gave them, by drawing up a clear chart showing when he is supposed to take all his regular medication. There is an important similarity, however, between the stories told by people at opposite ends of the spectrum as regards both knowledge construction and enactment of pill-taking: all these people succeed in presenting themselves as competent. If deciding is equated with constructing an acceptable story about the narrator doing the right thing, then all participants’ accounts present them as managing both to decide what to do and to do it. This success relates to the discursive framings visible in their accounts and explored in detail in the paper in Chapter 5: talking about how they came to know the right thing to do, for instance, people work to present

themselves as paying the right amount of attention to what doctors say, and doing the right amount of reading about their health and medication. Hence two very different accounts of health knowledge, such as Susan's and the account of calcium deposits given by Peter and Wendy in the paper, can both succeed in the same terms: the difference between them lies in their different assessments of how much health knowledge is the right amount. Rather than taking Susan's account to indicate a regrettable lack of autonomy or health literacy, the data here suggest that she is comfortable presenting herself as competent and agentic. This makes sense once agency is framed as relational; although Susan describes the ways in which she relies on other people, this description does not threaten her claim to competence and agency, because these are presented as shared accomplishments. Thus independence and autonomy appear to be optional elements of a presentable story; participants do not equate doing the right thing with doing it on one's own.

In Chapter 5, presenting oneself as doing the right thing is framed as identity work, an enterprise shaped by a collection of often-tacit normative discourses. These healthist and responsabilising discourses, rooted in the biomedical establishment but now extensively diffused beyond it, articulate and overlap with a broader grouping of discourses about independence. Together, these discourses shape an extensive body of biomedically-rooted research and debate about healthcare policy and practice within which autonomy is a goal commonly cited as an end in itself, its valorisation generally left unproblematised. Autonomy is also frequently identified as a reason to promote patient choice and self care, goals that are widely visible in NHS policy documents such as The Five Year Forward View [Stevens 2014]. Patient empowerment is often advocated in such documents, which feature a group of overlapping practical enterprises that all centre on information and choice: health literacy, health activation, shared decision making and risk communication.

A transfer from doctor to patient of evidence-based information is a key element of shared decision-making and risk communication, while health literacy aims to help patients seek, understand and think about such information [Edwards et al, 2013] and health activation aims to help them to 'use [it] to support .... informed consumer choices' [Hibbard 2017]. Informed choice is central to the measures through which The Five Year Forward View proposes to 'empower... patients to take much more control over their own care and treatment' [p7] – the section on empowerment includes plans to

‘improve the information to which people have access’ and to ‘to support people to manage their own health.... [by] making informed choices of treatment’.

These writings increasingly acknowledge the extent to which people rely on other people and on technologies to take care of themselves: Rapley [2008] discusses relational autonomy and distributed decision-making; Edwards et al [2013] emphasise that health literacy, too, is best seen as distributed, although their conception of distribution is limited to multiple encounters with other people while Rapley’s, like mine, includes interactions with non-human actors. Their contributions are complemented by those reviewed by Vassilev et al [2011], who focus on the role of social networks in the enactment of ‘chronic illness self-management’. Corbin and Strauss [1985] give a particularly detailed account of this role, describing it in terms of the three inseparably intertwined lines of work it involves. My own research approach relates particularly closely to two aspects of Corbin and Strauss’ account: I build on their discussion of ‘everyday work’ to adopt a broad focus that encompasses everyday household routines and identifies their close articulation with routine medication practices, and I extend their account of ‘biographical work’ both in my exploration of identity work in Chapter 5 and in the portrayal in Chapter 6 of ‘deciding’ as constructing a presentable story about oneself and one’s decisions and practices.

By exploring the way people come to take medication while they feel well, my research addresses questions that fall outside the remit of research focused on ‘chronic illness’ [Corbin and Strauss, 1985; Vassilev et al, 2011], ‘chronic multimorbidities’ [Pickard and Rogers 2012] or ‘longterm health conditions’ [Edwards et al 2013]. These terms are increasingly widely used and yet increasingly problematic. Aronowitz’ [2009] describes the convergence of the experience of ‘risk’ with the experience of ‘disease’ and lists some of its drivers, building on David Armstrong’s account [1995] of ‘Surveillance Medicine’; I review Armstrong’s seminal body of work on the construction of chronic illnesses in Chapter 1. The difficulty of defining a ‘condition’, and the articulations between diagnosis-as-category and diagnosis-as-process [Jutel and Nettleton, 2011], are discussed in Chapter 4. Here in Chapter 6, I suggest that the distinction between being at risk of future illness and having a current ‘morbidity’ is not a very helpful starting point for considering decisions and practices concerning longterm regular medication. Empirically, when I compared participants who had had heart problems with those who had not, I found no salient differences in the way people



speak about necessity and about taking their medication. This negative finding, used in Chapter 4 to consider the way necessity is constituted, was striking in view of the biomedical framing I began with at the start of the study: as a doctor I distinguish between people with and people without established cardiovascular disease, classing them respectively as candidates for secondary or primary prevention.

Constructing a plausible story to account for my findings was much easier without the constraint of a typology based on terms like ‘chronic illness’, ‘longterm conditions’ or ‘established cardiovascular disease’. Instead, the story I present here uses these terms only where they help to explain the way people present their medication as ‘necessary’. In the paper above, this presentation work itself takes its place within the web of discursively informed social practices that produce medication decisions and carry on their daily enactment. This practice-based story is used as the starting point for the last two chapters of the thesis. In Chapter 7, I draw on my findings about knowledge construction to discuss the relations between information, knowledge and expertise in the era of ‘e-scaped medicine’; I then bring the thesis full circle by returning to the biomedical context in which it originated, using Chapter 8 to consider the way the body of theoretical, population-based knowledge that is widely described as ‘evidence’ may be used by clinicians to help them care for individual patients.

## **Chapter 7: Information, knowledge and expertise**

### **Introduction**

In these last chapters of the thesis I discuss some of the theoretical implications of the empirical findings presented earlier; Chapter 7 explores the relationship between information and expertise, drawing on findings about the kinds of information and discursive framings referenced in accounts of statin decisions.

The question addressed here is, how do people construct and use knowledge within their medication practices? This question runs throughout the thesis: Chapters 3 and 4 consider different kinds of knowledge and asks why some kinds get used more than others; Chapter 5 looks at the tacit knowledge that contributes to the normative discourses which shape medication practices; and Chapter 6 situates knowledge construction within the web of social practices which produces and supports long-term pill-taking. The discussion in this chapter carries on where these empirical chapters leave off, presenting a more theoretical exploration of knowledge construction as a social practice and looking at the role of knowledge as a constituent of other social practices. This exploration builds on Sarah Nettleton's [2004] account of the emergence of e-scaped medicine, drawing on Pierre Bourdieu's [1990] discussion of different kinds of knowledge and on Harry Collins' [2014] model of different kinds of scientific expertise, and also referencing Deborah Lupton's discussions [1991; 1997a; 2012; 2013] of the reflexive consumer.

Two key features of Nettleton's account constitute a starting point for the story told here. The first, pointing to the 'e-scape' of her paper's title, concerns 'the dissemination of knowledges, or rather information, about health, illness, and disease'. Although this formulation seems to imply a relative lack of concern with a possible distinction between 'knowledges' and 'information', the second key feature of Nettleton's account is a typology of knowledges; she describes 'a shift from discursive knowledge to informational knowledge', explaining that informational knowledge is 'disembedded' from the 'beliefs, values, and theoretical underpinnings' that characterise discursive knowledge. This typology is discussed and developed here. After that, a further element of Nettleton's thesis, her discussion of the effect of the e-scape of information on the concept of medical expertise, is used to consider how Collins' account of the

constitution of scientific expertise can be extended to look at medical expertise in the era of what Nettleton terms informational medicine. The overall aim here is one suggested by Nettleton herself; following an account of the multiple sources from which patients can obtain information, she points out that ‘the ways in which users actually make use of such information clearly begs empirical scrutiny’. The following discussion is the result of such scrutiny.

### **Constructing usable knowledge**

It might seem that the project of reducing the incidence of cardiovascular disease by giving people statins should be a straightforward example of e-scaped informational medicine. Information about cardiovascular risk, formerly available only to doctors, is now available to almost everyone, and decisions about acting on this information, formerly made by doctors, can now be made by patients for themselves with the help of a non-clinical information handler (such as the receptionist at a gym) or a computer programme. Yet despite this apparent likelihood of a good fit, some aspects of Nettleton’s account are called into question by the story told in this thesis about the way theoretical knowledge gets used within preventive medication practices.

One aspect which seems incontrovertible is that the boundaries which used to confine ‘medical’ information to professional textbooks have become porous. As Nettleton describes, this has allowed the e-scape of information about health and disease in general, into newspapers and magazines and onto the TV and internet. Additionally, an individual can obtain far larger amounts of information about her own health or disease than she could possibly have obtained a few decades ago. There are several reasons for this. First, doctors measure more parameters more frequently, because of technological developments that enable them to do so and an associated shift in medical practice to embrace these developments, so there is more information available about a patient. Then, a doctor is likely to give a patient a far higher proportion of the available information about herself, in response to increasing democratisation and consumerisation of the relationship between them. These two reasons implicitly frame health, illness and disease as the concern of doctors and patients; however, a third highly salient shift over recent decades has been the broadening of this framing to cast taking care of one’s health as one of the responsibilities of a good citizen, and the related development of technologies such as self monitoring devices, widely available

testing kits, and online assessment questionnaires through which people can obtain an increasing amount of information directly, without asking a doctor.

This increased availability and use of biomedical information is one of many examples that clearly illustrate the e-scape phenomenon central to Nettleton's account. However, her typology of knowledge as either discursive or informational remains open to question, at least insofar as it is read as a neat binary classification. This study provides a good basis for questioning such a classification, because the standard explanation of how people come to take or not to take statins is that they make a decision using information about risk or cholesterol, both topics about which one would expect knowledge to be informational in nature. However, the findings presented here do not fit that standard explanation at all well, leading me to re-examine the notion of 'making a decision', as I do in Chapter 6. The findings also suggest a need to blur the distinction between discursive and informational knowledge, looking at the articulation between Nettleton's characterisation of informational knowledge and Bourdieu's characterisation of theoretical knowledge.

Nettleton's definition of informational knowledge as 'disembedded' echoes Giddens' [1991] use of the word in his account of modernity. Although Giddens applies it not to knowledge but to social institutions, writing of 'the "lifting out" of social relations from local contexts and their rearticulations across indefinite tracts of time-space' [p18], he relates this disembedding to 'modes of technical knowledge which [has] validity independent of the practitioners and clients who make use of [it]'. This account, like Nettleton's, seems at odds with Bourdieu's contention that theoretical knowledge is inevitably constrained by the habitus, an assemblage of locally shared tacit practical knowledge and values that determines what gets noticed and designated as an object to be known about. Bourdieu's point highlights a problem with the idea of informational knowledge which is particularly relevant to my focus here on the way knowledge gets used in practice; while one can think of examples of completely disembedded information, such as a phone number, such information can only be used by connecting it with some 'theoretical underpinnings', in this case knowledge about how to use a phone. This example also illustrates a further important point: while the knowledge required to enable someone to use a phone could probably be completely codified, it seldom is – this is usually practical, experiential knowledge, learned tacitly.

The claim I make here is that purely informational knowledge cannot inform or shape practices. Yet what people do is sometimes clearly shaped by theoretical knowledge; the challenge is to explain how this works, differentiating between informational and theoretical knowledge. To explore the ways in which knowledge informs action, a good starting point is the difference described in Chapter 3 between knowledge about cholesterol and knowledge about risk: in accounting for their actions, people reference knowledge about cholesterol but not knowledge about risk. Chapter 4 makes a first step towards understanding this difference, rooting it in the concept of distributed embodiment. The next step is to work backwards from the interface between knowledge and action, using the reconceptualization of ‘deciding’ put forward in Chapter 6. If deciding to do something is understood as constructing a comfortably presentable story in which it is ‘the right thing to do’, then the object of study is the kind of stories that combine to produce a decision, and hence to inform an action. This framing foregrounds the role knowledge plays in such stories.

This account articulates closely with the way Nettleton and Green [2014] explain change or lack of change in practices such as cycling, in terms of the habitus that renders or fails to render a possible new practice ‘thinkable’. The extra bit that needs adding to their explanation is a model of the way theoretical knowledge fits in, one which explains why knowledge about cholesterol gets used in deciding while knowledge about risk does not. A story based model can help do this, by looking at theoretical knowledge as a collection of stories whose characters include entities such as risk and cholesterol. In this model, the test that knowledge has to pass in order to inform practice is that it must be closely interconnected with the habitus; this means that at least some of the stories that constitute it must be grounded in experiential knowledge.

This idea can be clarified by looking at the example of knowledge about cholesterol. Participants in this study talk a lot about cholesterol; it is presented as a trigger for taking pills or as a goal of treatment, supporting the claim that knowledge about cholesterol does inform practices. Much of the knowledge indicated is purely theoretical, but it is never what Nettleton calls informational knowledge; it is always embedded in a discourse which includes beliefs and values, for instance about cholesterol being a bad thing, or a problem or ‘condition’ that one might treat with ‘healthy eating’. As well as this interconnection with beliefs and values, many participants also indicate that their knowledge about cholesterol is embedded within a

theoretical framework, for instance by referencing knowledge about different types of cholesterol or by indicating awareness that cholesterol is a type of fat. This embeddedness is what Judith Green [personal communication] has suggested calling conceptual density; in terms of stories, cholesterol is a character in several different stories people tell in these interviews.

To account for action, however, conceptual density is a necessary but not a sufficient condition, as may be seen by comparing cholesterol with risk. Theoretical knowledge about cholesterol is entangled with at least two kinds of practical knowledge that make sense of it and make it likelier that people will use it. First, many people talk about low-fat foods and reference information and values about which foods they should avoid eating because of their high cholesterol content – ‘we don’t eat much meat’ or ‘we never buy butter’ are frequent comments in the data – indicating that cholesterol is a character familiar to them from several everyday stories, tacitly but unequivocally identified as a bad thing. The second body of practical knowledge is indicated less frequently, but is clearly salient to those who did mention it: cholesterol matters because it can ‘fur up’ arteries, an analogy very familiar to people in a hard water area like the study site. The importance of analogies or metaphors as a way of grounding theoretical knowledge is highlighted by Reventlow et al’s [2008] account of women who talked about a building that is liable to collapse if its foundations are weak, or about a brittle porcelain ornament, when asked to explain their bone density results. These women linked their test results to possible future fractures, just as several of my participants specify that cholesterol ‘can give you’ a heart attack or a stroke; some go on explicitly to reference practical knowledge that heart attacks and strokes are very bad things, in either their own experience or that of a friend or relative, but even without such references the badness goes without saying, at least in this age group.

Risk, like cholesterol, is a character in several familiar stories, so it would seem to satisfy the requirement for conceptual density. Although many people lack detailed understanding of numerical risk estimates, which is confined to those involved in gambling or a few professions like epidemiology or selling insurance, most have tossed a coin, talked of possible futures as being ‘50:50’ or considered themselves unlikely to get a job if they are one of a hundred applicants. Such everyday examples suggest that most people do have a sufficient quantity of experiential knowledge of risk to confer

some conceptual density upon new information such as their cardiovascular risk estimate. This is what one would expect centuries after the step change Ian Hacking [1975] describes as ‘the emergence of probability’, a very rapid move in the 17<sup>th</sup> century to widespread development and application of the science of quantitative risk estimation; it is unsurprising that statistical information is a feature of everyday life in the 21<sup>st</sup> century.

Yet participants in this study make very little use of their own personal risk information. This may be because the stories cited above are counterbalanced by a fund of other stories, and these others are closely grounded in a collection of tacit practical knowledge and beliefs that have not changed as much as Hacking’s account might suggest.

Hacking describes a widely prevalent statistical discourse about chance, arising in the 17th century and superseding older discourses which centred on a belief in the inherent uncertainty and unreliability of any knowledge about the future. Giddens [1991] makes a related point in his characterisation of modernity: he considers the notion of fate as outmoded, suggesting that, in its place, ‘thinking in terms of risk... is ....a means of seeking to stabilise outcomes, a mode of colonising the future’ [p133]. This points to a second feature of fate in addition to the one relating to uncertainty: lack of control, implicit in pre-modern ideas about the impossibility of knowing ‘what the fates have in store’ – the present tense in this standard phrase implies that the fates have already determined the future, which would make trying to alter it pointless. While belief in predestination may no longer be prevalent, at least in its old religious forms, its legacy can be seen in a tacit scepticism about influencing the future; this scepticism competes with the theoretically-informed discourses of risk reduction underpinning the enterprises of preventive medicine and health promotion. This scepticism is illustrated by Davison et al’s [1991] findings in their lay epidemiology of coronary candidacy: to cite their famous example, everyone (including several of my participants) knows of an ‘Uncle Norman’, the heavy smoker who lived to a great age, as well as a slim non-smoker who had an early heart attack.

Knowledge about someone like Uncle Norman underlines a general point about the fallibility of risk estimates as a guide to what will happen to an individual, and thus makes it harder to tell a story in which it is ‘the right thing’ to take action now on the basis of being ‘at risk’ of heart problems in future. Other less directly relevant stories, too, militate against deciding to act upon risk information; every adult knows that the

future is uncertain, that plans quite often fail and that predictions are quite often wrong. Several participants in this study indicate awareness of this uncertainty, which is compounded by the fact that knowledge about future health risks is rooted in information about a large group of people; some participants specifically mention the inescapable weakness of using population-based information to inform individual decisions and actions. As cited in Chapter 3, for instance, someone explicitly contrasts population-based, statistical information unfavourably with '*the hard evidence*' of his own cholesterol results, which he is happy to act upon by taking statins.

There are just a few instances in the data where a participant does mention a numerical risk estimate they have been given, and indicates awareness of this relationship with a large group of other people. However, the way this link is made serves to translate the information into a more conceptually dense form; one participant says he thinks his risk level is not worrying because it is '*roughly normal*' for men his age, and another that she thought her level '*sounded quite high, compared with what other people talk about*'. Thus these unusual participants are using theoretical, quantitative information about risk to account for their medication decisions, but in order to make this use of it they first embed it within a discourse about comparisons with other people. This discourse, which Armstrong describes in his account [1995] of the problematisation of 'normality' as a key feature of Surveillance Medicine, incorporates tacit knowledge about gender- and age-related variation (which makes sense of a male participant's specifying that he is comparing himself with men his age) and the implicit value judgement that it is good to be '*roughly normal*'.

Alongside identifying one's levels of risk or cholesterol as normal, another way to construct and enact normality is to engage in 'normal' practices; for instance, as the findings presented in Chapter 6 show, knowing that taking statins is '*commonplace*' makes it easier to '*live with the idea that it's the right thing to do*'. The paper in Chapter 6 emphasises that this knowledge is largely practical, gained by everyday interaction with other people and reinforced by the embedding of medication practices within a web of other everyday household routines. 'Deciding' to do something is portrayed in this last paper as the process of constructing a comfortably presentable account of doing it, which requires the construction of knowledge that it is '*the right thing to do*'; as Nettleton and Green [2014] point out, such knowledge cannot be constructed without a tacit, experiential component.



This claim, that theoretical knowledge informs medication decisions and practices only when it is combined with practical knowledge, accords with accounts of the articulation between information and practice in two other contexts. First, Delmar [2010] writes about the methodological challenge of building credible generalisations in qualitative research. For the findings of a piece of research to be generalisable and usable by practitioners, Delmar suggests that the new knowledge has to have ‘recognisability’, a characteristic underpinned by a relationship with practical knowledge: ‘it is the experience from a similar situation that gives meaning. .... It is only when the recipient of the new knowledge gives form to the recognisable ... by a practical transformation of the situation that recognisability has been accomplished’. Delmar looks at the interaction between researcher and practitioner primarily from the researcher’s point of view; a second useful model, looking at the same interaction from the receiving end, comes from Gabbay and le May’s [2004] empirically grounded account of how GPs interact with evidence-based guidelines, using some and discarding others. Gabbay and le May describe the way GPs construct ‘mindlines’ which inform their practice; these mindlines incorporate some new knowledge obtained directly from evidence-based guidelines, but that theoretical knowledge is combined with two other constituents: the GP’s own experiential knowledge and the recommendation of respected colleagues. This model of the way usable knowledge is constituted and built can be used in other contexts; it offers a very good fit with my data, highlighting the salience of both practical knowledge and expert advice as central constituents of the knowledge participants reference in accounts of their medication decisions and practices. Having discussed this knowledge, I now turn to considering the concept of ‘expert advice’, particularly medical ‘expertise’.

## **Expertise**

The following discussion makes no apology for its close links with Collins’ [2014] account of scientific expertise, and indeed sets out to answer an almost identical question to the one in his title: are we all medical experts now? To address this question, Nettleton’s [2004] model of e-scaped, informational medicine is a good starting point, since it could be taken to suggest the answer that Yes, we are all medical experts now. However, the claim within this model that the concept of medical expertise has been dramatically changed raises more questions than it answers. Some of these questions are

surfaced by a statement Nettleton refers to: ‘The modern expert is someone who knows how to access knowledge efficiently and judiciously and who can form conceptual links between seemingly unrelated areas’ [Fraser and Greenhalgh, 2001]. One of Nettleton’s central points is that ‘the modern expert’ may well be a patient; Collins’ classification of different types of expertise is useful in considering what type of expertise a patient is likely to have, and what constitutes a ‘judicious’ way of accessing knowledge. A second question prompted by Fraser and Greenhalgh’s statement concerns the ways in which different types of knowledge may be acquired, and the extent to which ‘accessing’ describes the process of acquiring knowledge, while the point about the importance of ‘form[ing] conceptual links’ can itself be linked back to the idea that knowledge must have a minimum level of conceptual density before it becomes usable.

### **Types of expertise**

Collins offers a typology of expertises: ubiquitous expertise is exemplified by the mastery of a native language (thus it is ubiquitous only within a specified group); specialist expertise, the kind usually meant in casual references either to specialists or to expertise, is acquired through a lot of practice of a kind not undertaken by everyone in the group under consideration; and meta-expertise refers to the capacity to assess and choose between specialist experts. Collins subdivides the category of specialist expertise according to the type of tacit knowledge it requires; in one sub-category, all that is needed is ubiquitous knowledge about how to access information, for example by using the internet, while the other sub-category of specialist expertise requires tacit knowledge that can only be acquired by interaction with other specialist experts. It is this second, interactional type of expertise, then, that seems to characterise specialist expertise as he has defined it earlier, the kind that requires ‘10,000 hours of practice’ according to a widely accepted account. The dividing line between these two subcategories is the key point of relevance to considering the way people acquire and use knowledge about health and disease, separating knowledge you can acquire by reading from the ‘specialist tacit knowledge’ that you can only acquire through practical experience. As Collins is careful to point out, this distinction does not necessarily map onto a distinction between lay people and professionals; his point is easy to illustrate in the context of medical expertise, where people often acquire interactional expertise related to a disease they have lived with for many years. The distinction he is

describing, which seems closely related to the one Bourdieu draws between theoretical and practical knowledge, does not necessarily conflict with Nettleton's conception of the patient who is an expert: Collins' typology distinguishes between people who acquire lots of theoretical knowledge but no 'specialist tacit knowledge', and people whose practical knowledge contributes to an interactional expertise. Alongside his examination of the expertise of professional scientists, he identifies a particular category of 'experience-based' interactional experts, a category that is very useful for my exploration of expertise in the context of health and illness: a patient may become an experience-based expert by putting in a figurative 10,000 hours of living with a disease.

Returning to Nettleton's typology of informational or discursive knowledge, 'informational knowledge' maps neatly onto the group of three kinds of knowledge Collins suggests might better be classed as 'levels of specialist *information* rather than expertises' [p66, his italics]: beer-mat knowledge, popular understanding, and primary source knowledge, in ascending order of the quantity of information they involve. To obtain this information, as Nettleton points out, all that is needed is the largely tacit knowledge that enables people to read a magazine, watch TV or use the internet; the information is thus enabled to e-scape through boundaries that once restricted access it. But while these boundaries have become porous, there is a possible flaw in Nettleton's suggestion that informational knowledge may increasingly supersede discursive knowledge: Collins emphasises the distinction between primary source knowledge and interactional expertise, and the boundary underpinned by this distinction has not become porous. The existence of this boundary is perceptible to the interactional experts within it, although their knowledge of it is likely to be tacit and practical. In Collins' example [p30] of scientists who can only learn to build a TEA-laser by working alongside people who know how to do it, this knowledge is demonstrated by the material production of a working device.

For further examples of the salience of the boundary between primary source knowledge and interactional expertise, I draw on my own experiences, both as a doctor reading the social science literature about health, and as a novice attempting to learn how to contribute to that literature. Reading accounts that attempt to cross the boundary into the territory of biomedical expertise, I am sometimes aware of an uncomfortable feeling like that produced when someone who is not a native speaker of one's own language makes a joke. For example Timmermans and Haas' [2008] discussion of

diseases (in their call to establish a sociology of disease) feels strongly as if it is written from outside this boundary. This feeling challenges the authors' suggestion that 'sociologists should become experts in bio-measurements'. A realistic suggestion would be that they should acknowledge the limitations of their primary source knowledge, unless they are able to work closely within a group of doctors for several years. Similarly, coming from a purely biomedical background and looking at the boundary that surrounds social science expertise, it has taken several years of regular interaction with expert social scientists to become aware of the kind of expertise I lack, let alone to begin to acquire it. Even after these years I remain reliant on 'native speakers' to alert me when something I write or say evokes their discomfort. This discomfort indicates a key feature of interactional expertise: acquiring it is a discursively informed social practice, and the 'toe curling' effect of encountering someone who lacks it is an effect of the incongruity of framing, a clash between the largely tacit discourses that shape the interactional expert's account and the way the non-expert makes sense of their primary source knowledge. Such discourses are surfaced in my data in the accounts of participants who talk about choosing between different sources of information, a choice that requires what Collins terms meta-expertise. This is the expertise needed to choose which sources of information to trust.

### **Meta-expertise: 'accessing knowledge judiciously'**

As Nettleton says, most patients nowadays can get hold of biomedical information for themselves without being given it. What they may lack, however, is the interactional expertise to make use of it in decision making. Particularly once decision making is re-conceptualised as the process of constructing a presentable account of doing something, as I argue in Chapter 6 that it should be, seeking doctors' advice can be cast as a practice contributing to this deciding process. Advice-seeking itself requires a different kind of expertise, the meta-expertise used to rank a collection of pieces of information and advice and choose which to use. Several participants' accounts indicate that a course of action recommended by a doctor can be assumed to be the right thing to do, or that online information or magazines presented as originating from medical sources are better and more reliable than sources lacking this assumed stamp of quality. However, other participants challenge these assumptions, often explicitly, either citing examples of occasions where a particular doctor got it wrong or talking about the way '*medical*

*opinions change monthly*'. The paper in Chapter 5 describes the calibration work needed in order to construct an account one is comfortable presenting, balancing sensible advice-seeking against mindless obedience to doctors' orders.

Alongside information derived directly from biomedical sources, whether given by one's own individual doctor or obtained by reading the leaflet in the pill packet, even my middle aged and older participants often talk about also gathering information from other sources, such as magazines or the Internet; it is interesting to speculate that a younger group might well have indicated more reliance on such sources, using them to collect both information about their own bodies (often including comparators in the form of either population-based information or data from other people using the same type of measuring device) and information about health and health behaviours in general. In a younger group, too, it seems likely that the right amount of reliance on information from doctors would be smaller than it was in this study, while the right amount of direct information seeking would be greater, with a higher threshold before one risks presenting oneself as '*a hypochondriac*' or '*paranoid*', both tacit accusations that study participants worked to rebut. The rapid pace of the changes Nettleton [2004] describes as producing e-scaped medicine make it hard to draw inferences about what is going on now, even from fairly recent research. For example, Sillence et al [2007] describe the way people use online health information about 'menopause treatments' such as hormone replacement therapy; their conclusion, that 'despite the use of the Internet the physician was still seen as the primary source of information and advice' by their participants, may not apply to the next generation of middle aged women. Five years after Sillence et al's paper was published, Ziebland and Wyke [2012] highlight the rapid growth of a different kind of online information, discussing the ways people use the Internet to share accounts of their own experiences and other people's, and it seems certain that such sharing has become even more prevalent over the further five years since they wrote, and likely that its salience within decision making practices has increased.

While ways people gather and share health information are likely to be changing fast, making it challenging to generate micro-level, descriptive research findings upon which useful inferences can be built, theoretical debates have a longer shelf life. Deborah Lupton [1991; 1997a; 2012; 2013], for example, has explored and chronicled the evolution within sociological accounts of the reflexive consumer and, in recent years,

the impact on that consumer of health information generated by portable self-tracking or ‘mHealth’ devices. Reading a series of her papers in chronological order provides an interesting picture of the way she and others have moved from a focus on consumerism in relation to ‘seeking and evaluating ... health care’ [1991] towards accounts [2012, 2013] that examine the way people use directly accessed information alongside or instead of information and advice from a doctor. The early [1991] paper draws on a study of the ways people chose their GP; in Collins’ terms, this is a study about a meta-expertise, knowing how to choose the most trustworthy expert. Lupton foregrounds the finding that this choice seems to be informed largely by practical knowledge of an individual doctor, and that using theoretical knowledge was explicitly rejected by her participants in ways that indicated an active rejection of the consumerist discourse: in this account, they present making an informed choice between doctors as incompatible with norms about the way a good patient carries on.

Two decades later, these same norms are still visible in my data, although sometimes in the context of accounts in which the speaker identifies themselves as belonging to ‘the generation that was brought up... to believe that what doctors said is right’. The paper within Chapter 5 juxtaposes these accounts, which indicate the trust in and deference to doctors described as widespread by Lupton et al in 1991, with others in which this deference is explicitly cast as a failing by one interviewee when describing her husband’s relationship with medical advice. In a later paper [1997a] Lupton identifies the same rival discourses, which she refers to as passivity and consumerism, and discusses the way patients ‘may pursue both .... [these two] position[s] simultaneously or variously’. I extend this discussion in Chapter 5, linking it with Will and Weiner’s [2014] account of people moving smoothly between multiple discourses when talking about their health practices, and pointing out that this apparently effortless movement is underpinned by the visible work my interviewees do to defend themselves against two competing threats to a presentable identity: being too passive a recipient of medical advice, and being over-active in collecting information for oneself and using it to act against medical advice. Thus the shift these data indicate is not a clean break with trust and deference in favour of autonomous choice and action, but a move to accommodate both the old and the new discourses simultaneously.

Returning to Sillence et al’s [2007] study of women looking for menopause information, the authors report that their participants subjected online information to

two key tests in order to decide whether or not to use it, assessing first its trustworthiness and then its relevance to the individual participant's situation. The first test makes explicit the salience of specialist expertise to Sillence et al's participants: people spoke of preferring sites 'that were run by reputable organizations or had a medical or expert "feel"'. They also mentioned distrusting sites which could be seen to be sponsored by drug companies, illustrating another point Collins makes, that what is widely perceived to be distinctive about scientists (and, presumably, about doctors too) is not their relationship with and knowledge of 'nature' but their ethos – 'the values that drive their lives, and their aspirations...to live by a set of norms ....[which] are good in themselves' [pp124-6]. Several of my participants, too, talk about trusting doctors and following their advice; that this is a sensible thing to do is often tacitly implied and sometimes stated explicitly, while just a few people problematise that assumption and indicate that it is sensible to seek information elsewhere as well (though never instead). This relates back to Hacking's [1975] account of the old meaning of 'probability': prior to the emergence of the statistical meaning of probability in the 17<sup>th</sup> century, a 'probable' statement meant one 'which is attested by an authority'. It seems that people may still be more likely to take action on the basis of expert advice, inherently discursive knowledge in Nettleton's terms, than they are on the basis of statistical risk information which epitomises informational knowledge.

Another of Sillence et al's findings supports the idea that theoretical knowledge is only likely to be used to inform action when it articulates closely with practical knowledge, and that stories about people like oneself are one way to strengthen this articulation; Sillence et al found that the other test their participants used to decide whether to heed online information, in addition to assessing the trustworthiness of its source, was its apparent relevance to their own circumstances. This relevance was constituted by two factors the authors list separately. First, people sought information which not only matched their specific queries but which also 'supported their own viewpoint' rather than clashing with what they already knew and believed; secondly, they preferred information that included 'personalised content', stories about someone they could identify with. This second finding accords with Casiday's [2007] report that, in her study of the way parents talked about deciding whether to give their child the MMR vaccine, 'medical practitioners' advice was generally trusted when they showed concern for the individual child... and shared their own stories about making such decisions as a

parent or about positive experiences of MMR vaccination’. Similarly, in my own data, participants explicitly state their preference for acting upon advice that is clearly relevant to *‘[their] particular case’*, rather than *‘being put on, a regime of drugs which has been designed for an average person’*; the challenge this preference poses for doctors attempting to offer ‘evidence-based’ advice is discussed in Chapter 8.

This assessment of personal relevance, Sillence et al report, appeared to trump the trustworthy source test where the two pointed in opposite directions: ‘A number of medically credible sites were ignored because they lacked sufficient social identification markers’. This echoes Delmar’s [2010] thesis that ‘recognisability’ is the key requirement for new knowledge to influence practice, and supports the claim made here that for information to be used, it needs both conceptual density and integration with existing practical knowledge. In terms of stories, a story that taking pills is the right thing to do, for instance, is only likely to be robust if it is formed of a collection of other stories which hang together, and is only likely to lead someone actually to take pills if some of the constituent stories within that collection involve practical knowledge. The next question, then, concerns the way different stories are made to hang together to constitute a usable body of knowledge. This question is pertinent to both the two topics I have considered so far in this chapter; as well as continuing my account of the way knowledge is constructed, I now examine the interactional expertise required to construct it.

### **‘Forming conceptual links’: combining pieces of information into usable knowledge**

For a collection of pieces of information to inform practice, they need to be combined into a coherent body of knowledge. This is not an issue considered directly in Nettleton’s account of informational, e-scaped medicine, but she does cite an article in which Fraser and Greenhalgh [2001] make recommendations about how to educate someone to become a doctor. Defining the ‘modern expert’ as someone ‘who can form conceptual links between seemingly unrelated areas’, Fraser and Greenhalgh contrast this with an older definition that casts an expert as someone with lots of knowledge. Their recommendations are directed towards educating doctors to become modern experts, capable of adapting to the changes that characterise the complex systems in which they work, and of working with uncertainty, handling ‘emerging information



from different sources'. Fraser and Greenhalgh's article is mainly focused on the educational methods through which this modern expertise might be fostered; it is complemented by Mol's [2002] ethnographic study of the way a hospital team works to try and help someone with painful legs. Mol emphasises the necessity of combining the often-conflicting information that emerges from different sources, using it to generate a story which informs treatment decisions. The healthcare team she studies asks 'not "what is the matter?" but... "what to do?"' [p69]; similarly, the discussion here is focused not on what people know but rather on the way they use knowledge within everyday practices.

Mol offers a helpfully detailed account of several alternative approaches employed to construct usable knowledge about an individual with painful legs, starting out by collecting lots of different kinds of information which must then be used to assemble a coherent story. She describes two groups of strategies or 'modes of co-ordination'. The first is addition: different pieces of information are either simply put together so that one reinforces the other, or subtracted so that one piece of information cancels the other one out, which sometimes requires agreement about a hierarchy of types of information. Mol's second mode of co-ordination is calibration, where translation mechanisms are agreed so as to bridge the gap between seemingly incommensurable types of information. These strategies are visible in the interview data presented in this thesis: my participants talk about different kinds of information that agree or conflict, and they indicate various ways of resolving conflicts, just as Mol's doctor participants do. The work of combining haptic information (and embodied memories) with tests results, in circumstances where these different kinds of information suggest differing courses of action, is particularly salient in the context of taking preventive medication; people are considering whether or not to take medication while feeling well, often on the basis of test results which are understood to provide '*hard evidence*' of a problem, so these two kinds of information point to two different courses of action.

Thus a key question addressed in this thesis concerns the way people resolve a clash between two kinds of information, one a collection of sensations and memories of sensations, the other a collection of explicit, theoretical information. Most accounts in the data fit Mol's 'addition' model, where one kind of information supports another, or else one simply trumps the other where the two disagree, although there are indications

that this combination process is sometimes difficult and uncomfortable when it involves subtraction rather than addition.

Several participants speak explicitly about the way their trust in haptic information, such as feeling well, was reduced by suddenly having a heart attack. Many such participants tell particularly detailed stories about their various test results, which trump bodily sensations, ranking above them in the hierarchical process Mol describes; some visibly echo the point she makes about combining two different kinds of information, that one kind ‘show[s] “reality”’ while the other kind of information only ‘makes things “seem”’ [p82] – in my participants’ stories, the test results show an implicitly real problem even though feeling well makes it seem that there is nothing wrong. Horlick-Jones [2011] describes this phenomenon, drawing on his experience of having had cancer, as a loss of ‘everyday health competence’; he situates this competence amongst other ‘mundane recipe-like expectations and routines in the social organisation of everyday life’ which inform practical reasoning. This framing accords with the argument presented in Chapter 6 that ‘deciding what to do’ is most helpfully cast as a social practice, carried on within a web of everyday routines. Assessing one’s state of health is one of the tasks which together constitute the work of living with a chronic illness, and also, these findings suggest, the work of living with memories of a serious acute illness in the past. This task can be described as constructing a coherent story about one’s state of health, a story which needs to be plausible to oneself as well as supporting an acceptable presentation to others.

The paper in Chapter 5 draws on the literature about the work of living with chronic illness, and hence relates to the notion of the expert patient, a notion explored further here. Some level of knowledge about one’s own body can be seen in Collin’s terms as a ubiquitous expertise, one which everyone acquires by my participants’ age. In people who have experienced a chronic illness, this ubiquitous expertise is highly developed and contributes to a specialist interactional expertise which also incorporates a body of both practical and theoretical knowledge about that particular illness, knowledge which may well also be applicable to some aspects of other chronic illnesses. Collins’ account clarifies the idea of the expert patient; this widely used term is sometimes used in one of two unhelpfully narrow ways, implying either that what the expert patient knows about is mainly her own body and her own preferences and circumstances (an extension of the old injunction to doctors to view the consultation as ‘a meeting of experts’ in which the

doctor knows evidence-based medical facts while the patient knows about herself), or that an expert patient is someone who can work within an ‘informational medicine’ framing, using information she can obtain online, as Nettleton suggests. As Collins explains, Nettleton’s ‘expert patient’ can certainly collect as much primary source information as her doctor can, reading the same journals and guidelines, but she is likely to lack the interactional expertise needed to make use of this pile of information. A more nuanced and useful account of the expert patient features in Britten et al’s [2015] case study of the way people with diabetes worked alongside doctors to decide about possible new drugs: these people are clearly examples of Collins’ experience-based, contributory experts, using two kinds of knowledge in combination: practical knowledge about living with diabetes, and theoretical knowledge which they have acquired not only by reading but also by interacting with a community of other diabetes experts, both patients and doctors.

Thus constructing usable knowledge is an inescapably social practice, one in which ‘arrays of activity’ [Schatzki, 2001] are informed and shaped by discursive frameworks. Once constructed, new knowledge gets used only when the discourses that frame it articulate closely with those framing existing, already-accepted knowledge and practices, an articulation which makes the new knowledge (and new practices informed by it) ‘thinkable’. This story accords with Bourdieu’s [1990] account of practical and theoretical knowledge, in which tacit, experiential knowledge and locally-shared values inform practices while theoretical, explicitly codifiable knowledge makes only an indirect contribution to determining what people do. Theoretical knowledge may well be conceptually dense, with multiple ‘conceptual links between...[different] areas’, but such knowledge will only influence what people do if some of these linked areas are grounded in a body of tacit knowledge and values which engender what Bourdieu calls ‘the feel for the social game’ [p29]. This is illustrated by a point made in Chapter 3 about the different ways in which prevention is conceptualised by different groups, and was the theme of a talk that prompted some discussion with the medical audience to whom I presented it (Polak, 2015): in considering statins, doctors are engaged in a game of risk reduction, which they call prevention. However, this biomedical discourse about prevention has not become widely shared, and so patients are unlikely to share a feel for that particular game. Instead, the findings suggest that they are working within a different discursive framing of the concept of prevention, one in which it means that

something bad is prevented from happening. In this second discourse, uncertainty is framed as a problem which weakens the link between knowledge and action, whereas uncertainty, likelihood and risk, tamed (in Hacking's terms) into statistical certainty, are central to the biomedical conception of prevention.

So in Fraser and Greenhalgh's list of the modern expert's attributes, their inclusion of the ability to 'form conceptual links' elides a more complicated story, one which accords with Bourdieu's account of the habitus and Collins' account of interactional expertise: the rules of 'the social game' go without saying and indeed defy attempts at codification, being learned only through prolonged interaction with experienced players of that game. A person who just collects a pile of information and identifies some links within it, even 'links between seemingly unrelated areas', is not what is widely regarded as a 'specialist' or a 'real expert', the kind of person Collins describes as an interactional expert. Collins agrees with Nettleton that nowadays anyone can obtain an unlimited supply of primary source knowledge, which has fully e-scaped from the old medical textbooks. However, the tacit discursive knowledge that characterises functional expertise, enabling someone to decide what to do in response to a pile of information, does not (and cannot, in Collins' model) leak freely out of the biomedical community, because it can be acquired only by means of interaction with members of that community. It seems that Nettleton's porous boundary between general and medical knowledge can more accurately be described as a semi-permeable membrane, letting some things through but not others.

Discourses about risk and prevention are an example of something that seems not to have leaked through this semi-permeable barrier. In contrast, in the case of cholesterol a good deal of tacit discursive knowledge is referenced by my participants. As well as framing their theoretical knowledge, this experiential knowledge about low-fat spreads and eating less meat gets used by articulating with a broader discourse about having the power and the responsibility to look after one's body, the discourse Crawford [1980] names 'healthism'. At the core of healthism is the belief that what people do can be construed as acting on their choices. This belief, which pervades many areas of biomedical research and practice, colours the enterprise of evidence-based medicine in ways that are discussed in the next chapter. In that discussion I build on some of the ideas explored in the current chapter, suggesting that the remit of evidence-based medicine might usefully be extended to consider not only the growing pile of theoretical

knowledge about health and disease but also the ways in which this knowledge is used in practice.

## **Chapter 8: Using evidence based medicine in clinical practice**

### **Introduction**

This final chapter brings the thesis back to the pragmatic biomedical focus with which it began, foregrounding the relevance of my findings to clinical practice and health policy making. The research began by asking ‘How do people decide about statins?’, a question which has since evolved and broadened into ‘How do people who are offered statins come to take (or not take) them?’. As part of this process of evolution, my conception of ‘deciding’ has changed. From considering a purely cognitive process, I have shifted to framing deciding as a social practice whose product is a story that one is comfortable presenting to oneself and to others, a story of doing ‘the right thing’. My data suggest that to be presentable, this story has to be clear and unequivocal; to be comfortable talking about pill taking, for example, one needs to present the pills as necessary rather than as chosen. This reframing of decision making has several implications for the enterprise known as evidence based medicine (EBM), a collection of practices whose intended product can broadly be characterised as better decisions about health interventions. Discussing EBM is a return to the two topics identified in Chapter 1 as central to the thesis, shared decision making and preventive medicine; facilitating evidence-informed decision making is a key constituent of EBM, and decisions about prevention rest particularly heavily on population based evidence.

Alongside my findings about the way people talk about their medication practices, I draw here on a medical perspective. As a GP I am charged with two tasks: to empower my patients by involving them in decisions, and to improve population health by getting eligible people to take statins. The research presented here was prompted by the difficulty of reconciling these tasks, of accomplishing either of them, and of ending the consultation with a plan that the patient feels comfortably certain about. Addressing patients’ need for certainty within the clinical task of facilitating evidence based decision making is especially challenging when decisions concern preventive interventions, so the enterprise of offering preventive medication is a fertile source of illustrations that highlight the difficulty of constructing certainty in an evidence based clinical consultation. The following account of this difficulty draws particularly on

findings presented in Chapters 3, 4 and 5 concerning the cognitive work involved in decision making, and situates itself as a contribution to debates about EBM. Within these debates I focus particularly on Greenhalgh, Howick and Maskrey's [2014] essay about the hoped-for renaissance of an improved 'real EBM', using this account as the starting point for my exploration of the way evidence about a population may be used to help an individual construct a presentable story about the right thing to do.

Greenhalgh et al begin their essay by suggesting that EBM may be 'a movement in crisis'. They go on to highlight several features of EBM that they cast as problems, and propose changes to mitigate these. Some of these changes address concerns about the ways in which quantitative evidence is generated, a topic beyond the scope of this thesis. However, the essay also considers two other topics that are highly pertinent to my discussion: the way evidence gets used in clinical practice, and the kinds of knowledge that are to be classed as evidence. Regarding evidence use, Greenhalgh et al argue that individual benefit, represented as maximised by 'the ethical care of the patient', should be a central aim of their 'real EBM'. They recommend that 'evidence must be individualised for the patient' to ensure that 'individual patients get optimal treatment'. While this recommendation has implications for those who generate evidence, it can only be met by the clinician who talks to a patient. Meeting it is particularly challenging in the context of evidence based interventions whose purpose is prevention; establishing the problem that needs solving is less straightforward in this situation than it is when the patient presents concerns about current pain or distress, and the consultation is further complicated by the need to talk about the uncertainty that is inherent in the enterprise of risk reduction. I begin my discussion by examining these special challenges, building on the account offered in Chapters 3 and 4 of the role of risk information and uncertainty in accounts of medication decisions and practices.

Later in the chapter, I consider some of the moral discourses that complicate the definition of 'ethical care', discourses that inform the practices through which a clinician works to provide 'optimal treatment' to the individual patient in front of her. I build on Kelly et al's [2015] discussion of the value laden character of every aspect of EBM, including judgements about what constitutes a good research question or good evidence, to explore the implications of Greenhalgh et al's call for a 'broader and more interdisciplinary' research agenda that includes 'qualitative research to elucidate the logic of care'. Drawing on Annemarie Mol's [2008] examination of the logic of care,

which she compares with ‘the logic of choice’, I argue that the ‘real EBM’ project would be strengthened by an account that explicitly raises the prominence of research about the way evidence is used by clinicians and patients, a move which, I suggest, would require an increase in the respect widely accorded to qualitative research. My argument rests on a finding central to the thesis: an account centred on choice is inadequate to explain how people come to take statins. This inadequacy challenges accounts of shared decision making in which the clinician’s role centres on helping patients make choices by providing them with evidence-based information. Qualitative research is needed to extend and deepen understanding of the work involved in using evidence to inform a clinical consultation.

### **Offering evidence based prevention: the problem of uncertainty**

*Don: A GP would have to say ‘Yes! aspirins would definitely help...your particular case.’*

*Interviewer: So, ‘Out of 100 people exactly like you they’ll help 10’ wouldn’t do it?*

*Don: No. Exactly, that’s right.*

*Geoff: I don’t particularly like .... being put on a regime of drugs which has been designed for an average person, or a person who falls into a very very very large category.*

As a clinician, patients often ask me about an intervention ‘Do I really need it?’ This focus on ‘need’ is echoed repeatedly within participants’ accounts of their medication decisions and discussed in Chapters 4 and 5; the data excerpts above are among those used in Chapters 3 and 4 to foreground the role of certainty in accounts of taking medication and to illustrate the high value participants accord to the individual applicability of evidence. To summarise, certainty that one ‘really needs’ medication is an essential constituent of the defence that participants offer against the tacit accusation that they are willing pill takers. ‘Need’ is a characteristic of the relation between a participant and their medication; in these data it rests on having a current condition, an entity requiring medication to control or treat it. As well as information about the present state of one’s body, such as feeling ill or having a high cholesterol level, certainty about needing medication may be built on knowledge about the past, such as memories of feeling ill or of being told that one was having a heart attack. Information



about the future, such as the probability of a future heart attack, is almost never used by my participants to support their claims to need medication. Some participants (for instance Don and Geoff, quoted above) explicitly cast such information as lacking two essential and conjoined characteristics, certainty and personal applicability. The problem I highlight here, stated simply, is that evidence based medicine (EBM) cannot provide information with either of these characteristics. However, it is simplistic to regard either certainty or personal applicability as binary, either present or absent; for clinicians, the challenge is to maximise their presence. As a clinician, meeting this challenge is one constituent of my overall objective, which is to help a patient reach an evidence-informed decision that they are comfortable with.

I approach this issue from a biomedical perspective; having identified the salience of certainty and personal applicability within participants' accounts of how they use various kinds of information to establish taking regular medication as 'the right thing to do', I move now to considering the implications of these findings for doctors who have to answer when a patient asks 'Do I need this intervention?'. I make no attempt to explore how doctors actually come to answer this question, but focus only on the relatively limited challenge of answering it in a rational, evidence based way. To explore this challenge, a good starting point is an excerpt, cited in Chapter 3, in which Larry reports what his doctor said:

*'I said to him 'do I need to take all these tablets?', and he pointed his finger at me and he said 'if you want to live a normal life, you take the tablets and you'll live to be an old man'..... So, I have always taken my tablets'*

This account of the doctor's reply cannot be used as the basis of robust inferences about what Larry understood; neither can such data be used for inferring what the doctor actually said. Nonetheless the excerpt offers useful clues about the role of this and similar remembered remarks by doctors, remarks that underpin an account of definitely needing the tablets. Such accounts serve to distinguish the participant from 'other people' who take tablets that they do not really need. This does not imply that Larry believes that the tablets will enable him to live to be old; elsewhere in the interview he sadly explains that he has been warned that he probably will not live to be an old man. What he does get from the doctor is definite advice whose personal applicability to him is underlined by the pointing finger – Larry accompanies the story with a vividly mimed

wagging finger. This advice is the basis of his decision; ‘always taking the tablets’ is presented with a comfortable degree of certainty, both to and by Larry, as being the right thing to do.

The doctor’s reported advice illustrates two separate facets of certainty: the certainty that the tablets can cause someone to live to be old, and the certainty that they will have this effect on Larry. These two facets indicate two distinct challenges for the enterprise of EBM: establishing the likelihood that the tablets work in a large group of people, and establishing whether this likelihood applies to Larry.

### **Do the tablets work? Measuring and communicating probabilities**

Establishing the benefit of an intervention in a large group is the core work of EBM. It is carried on according to a set of explicit rules which enable its practitioners to evaluate the robustness of the evidence they generate and use. In recent years a further, closely related task has gained prominence, that of communicating this evidence to patients; some of my findings can be seen as contributing to the growing body of both quantitative and qualitative evidence about the different ways in which this communication is done. It is this second task, evidence communication, that is of interest to me. In the thesis I therefore bracket any consideration of the robustness of the evidence that an intervention is beneficial to a large group of people; what matters to me as a GP is how I use that evidence to advise an individual whether or not to try the intervention. Explaining the probability of benefit is widely portrayed as central to this task; Greenhalgh et al, for example, recommend that, to ‘individualise... evidence... for the patient, research findings [should] be expressed in ways that most people will understand.... [using] tools that contain quantitative estimates of risk and benefit’. In Chapter 4 I present findings that indicate two problems with such recommendations. First, quantitative estimates are unlikely to be very effective in helping people build the certain knowledge that informs health decision making and practices. Secondly, what it is that ‘most people will understand’ is hopelessly slippery. This is shown with exemplary clarity by Misselbrook and Armstrong’s [2001] comparison of several different widely used formats for expressing information about the risks of high blood pressure and the benefits of treatment to lower it: the authors report that participants given the same information in different ways take very different decisions about blood pressure medication.

Thus the way people use information depends on the way in which that information is presented. This finding constitutes a challenge to positivist assumptions that are widely visible but seldom problematised in discussions of EBM in general and ‘risk communication’ in particular. The effect of such assumptions is exemplified by a recent legal ruling in the UK that a patient cannot be deemed to have consented to treatment unless she has been informed of ‘all material risks’ [Sokol 2015], a statement implying that there exists both a stable, unproblematic definition of a material risk and a method of informing the patient in a value neutral way about what it means. Misselbrook and Armstrong’s findings suggest that all risk communication is inherently value laden. They highlight the insurmountable challenge of trying to present a patient with ‘facts’ that are not coloured by a framing derived from the clinician’s own preferences. In the context of interventions whose rationale is to prevent future illness, the challenge of communicating about evidence is compounded by a problem highlighted in Chapter 4: whereas doctors ‘equate prevention with risk reduction’, patients may not, and are ‘likely to accept medication such as statins primarily in order to treat a definite current problem’ [Polak, 2016]. The potential impact of this potential mismatch of perspectives on a clinical encounter is generally elided from debates about risk communication, as discussed at a conference for clinical academics [Polak 2015].

Deciding about and taking statins, or any other preventive medication, is a particularly clear example of the difficulty of constructing certainty by using evidence about large groups of people, because the evidence, however robust and certain about what statins do to the population, is that only a small proportion of the population will benefit, and then only over several years. The problem with using population based evidence to inform an individual decision rests on Keynes’ [1921] point that ‘general laws amongst masses of phenomena’ cannot reduce or remove ‘the uncertainty of each particular case’ [p382]. Evidence based guidelines rest on ‘general laws’ whose robustness is quantified using statistical tools such as confidence intervals. This emphasis on statistical robustness risks diverting attention from its limitations, tempting practitioners to elide an important distinction; there is no connection between two entities: the precision with which risk can be calculated in relation to a future event within a large group of people, and the irreducible uncertainty of predictions about what will happen to one individual. In the consulting room I find that this irreducible uncertainty is most clearly conveyed to a patient by talking about the absence of a crystal ball, following this up with a story

about large numbers of other people. As this approach highlights the two characteristics of information that Don and Geoff explicitly reject in the excerpts cited above, it is unsurprising that it requires some hard work to use it within a conversation that produces a comfortably agreed plan of action, the primary goal of any consultation. This difficulty is illustrated by Summerskill and Pope's [2002] description of doctors' talk about offering preventive medication; their participants reported encounters in which a patient worked to move the doctor away from presenting the evidence, instead asking for the doctor's own advice about what to do. Using evidence to construct this personalised advice is the second (and more interesting) half of the problem of bringing EBM into everyday clinical practice.

### **Will the tablets help me? Applying general information to a particular case**

The word sometimes used for the process of applying evidence to an individual case, 'translation', implies a simple switch between different ways of presenting a given body of information. This formulation fails to highlight the co-construction work the clinician and the patient have to do in order generate knowledge that the individual can use. Population-based information is just one constituent of this knowledge, and communicating information is just one element of the clinician's job. In this section of my discussion I open the black box to which the other elements of the job are often consigned by other accounts.

When offered medication, an individual patient wants to know how likely it is that she will be helped by it. This likelihood depends on the answers to two questions. The first question is considered above; it is answered by collecting information about the medication's effects on a large group of people, establishing how many people in the group are helped by it and to what extent. Methods for answering this question are the subject of an extensive academic literature. The second question builds on the answer to the first: given that the medication will help a certain percentage of people in the large group, how likely is it to help one particular individual? Methods for answering this question are less often discussed. The answer depends on the number and salience of similarities between the particular individual and the people in the large group studied; evidence derived from studying a group will only apply to an individual where there is a close match between that individual and the study group.

The task of assessing this match is an aspect of Greenhalgh et al's 'real EBM' project that I am keen to problematise here. In their essay, they follow the statement that 'evidence must be individualised for the patient' with a section about clear presentation of the evidence; this appears to elide the central problem of individualisation, although they do identify the need to 'accommodate ...the patient's clinical and personal idiosyncrasies' as a fundamental goal of earlier iterations of EBM. To accommodate 'idiosyncrasies' it is necessary first to identify them, and then to match them with attributes of the study group involved in generating the evidence. There seems to be no satisfactory word for this matching process, but I propose a way of thinking about it, starting by emphasising its symmetry with the problem of generalising. Research evidence consists of generalisations, and what interests me is the challenge of making use of these generalisations in talking with a particular patient about their health practices. Although the 'individuals' considered in the methodological literature about generalising are cases rather than people, there are useful parallels between the problem of constructing generalisations and the problem of applying them to individuals.

Within the literature about generalising, many authors debate the challenges of using knowledge about particular cases to build valid generalisations applicable to a wide range of cases. Delmar [2010], for example, uses the motto of a hospital where she works – "The individual is like no others, like some others and like all others" – to clarify her contention that the central feature that makes generalising from a specific situation problematic is 'the doubleness of the situation as being both typical and unique'. This same doubleness makes it equally problematic to take knowledge based on a generalisation ('evidence') and use it to decide what to do in a specific situation. Delmar's formulation helpfully raises the individual's unique characteristics to the same level of salience as their similarities, the collection of shared attributes that allow them to be seen as 'typical' members of a group about which evidence may be constructed. This is a small but significant move from talking about 'idiosyncrasies', a term which implicitly casts the group as largely uniform in all important respects, with individual differences relegated to the side of the picture.

For a doctor or a patient who wants to determine the applicability of general information to a particular individual's situation, the key step is deciding which differences are important – which individual characteristics need to match the

characteristics of a large study group if one is to apply information about the group to an individual, and which individual differences can the doctor and the patient agree to relegate as unimportant? Assessing importance is clearly a value laden process, one that will depend on who does it and which yardstick is chosen for calibration. For example, as a doctor talking about statins with a patient, I consider their history of cardiovascular disease as a very important characteristic to match, because the evidence rests heavily on trials in which all participants in a study group shared that characteristic, and so evidence based guidance about statin use differs significantly depending on whether or not someone has been shown to have cardiovascular disease. In elevating this distinction (between primary and secondary prevention) to a status of high importance I am following the norms of the biomedical community which currently owns the EBM rule book, but it is possible that other, possibly competing yardsticks could be introduced, particularly if that ownership were to become more widely shared in future. Research questions could go beyond simply refining the existing biomedical yardsticks; rather than simply recruiting a group of participants who share biomedical characteristics such as age, gender or past medical history, a study could select its participants using criteria such as living above the 10<sup>th</sup> floor or seeing a close relative every day. Such a study could generate evidence about groups of people who share these criteria, and enable comparisons between, for instance, people who live high up and people who live closer to the ground. This broadening of the research agenda is one of Greenhalgh et al's recommendations for the development of real EBM.

There is an obvious appeal to including as many characteristics as possible in the group designated as 'important', because the more detailed and multifaceted the match between the individual and the study group, the more likely it becomes that what works in the group will work for that individual. To improve this match, authors such as Greenhalgh et al call for researchers to generate evidence about a more diverse range of populations, particularly citing the need for evidence that is likely to be applicable to people with multimorbidity. This approach helps to improve the fit between individual and population as regards the list of medical conditions. However, a perfect match is impossible unless one disregards other characteristics not on that list. It is possible to delineate an infinite number of separate characteristics, so either one has to take a decision to stop delineating, designating some characteristics as unimportant, or else one has to accept that each individual is completely unique, a stance that is clearly not

tenable: if an individual is not identified, in Delmar's terms, as 'like some others' in some respects, then it would be impossible to draw on any knowledge about others when attempting to help that individual. This would nullify the usefulness of clinicians' interactional expertise, applying not only to their theoretical knowledge about 'evidence' but also to the experiential knowledge they have gained by interacting with other patients.

For those engaged in the practice of clinical care, the central challenge is to help an individual by drawing on knowledge about other people, casting the individual simultaneously as both 'unique' and 'typical'. The research presented in this thesis did not set out to look at what clinicians do, but its findings nonetheless have implications both for clinical practice and for debates about EBM. In the next section of this chapter I draw on my findings to consider two enterprises, the theoretical enterprise of establishing the way 'good care' is constituted and the practical one of delivering that care.

### **Offering clinical care to a unique individual**

Those who seek to refine and practise EBM frame it as a way of improving clinical care and public health. Kelly et al [2015], discussing 'the importance of values in evidence based medicine', describe the originators of the EBM project as taking 'the best interests of the patient' as their primary goal. Greenhalgh, Howick and Maskrey [2014] echo this in their statement that 'real evidence based medicine... makes the ethical care of the patient its top priority'; the goal of their proposed renaissance of the EBM movement is to help 'individual patients get optimal treatment'. These framings raise questions about what constitutes these 'best' interests, who gets to define 'optimal' treatment, and how 'the patient' is identified. Foregrounding these questions makes it clear that they have multiple answers, each of which makes sense within a different normative discourse. A sketch of these discourses and the articulations between them is needed to underpin the story I want to tell later in this chapter, a story that underpins my argument about the way research findings are used in clinical encounters.

#### **'The ethical care of the patient': normative discourses within the EBM project**

The central argument of Kelly et al's [2015] essay is that every aspect of EBM incorporates and is shaped by values. These moral discourses are visible throughout

Greenhalgh et al's account of real EBM; in an explicitly normative account, the authors offer a collection of detailed recommendations for improving EBM. By shifting from 'traditional' to 'real' EBM, Greenhalgh et al aim to do away with 'mechanical rule following' while still continuing to maximise the use of robust evidence in clinical and public health practice. The improvements they propose concern two groups of practices that combine to constitute EBM: the practices through which evidence is generated, and those through which that evidence gets used.

### ***Generating evidence***

Evidence generation is widely seen as the core work of traditional EBM. Discussing it is beyond the scope of this thesis, except insofar as it articulates with the work of using evidence. This articulation centres on the hierarchy of different types of evidence that is visible in the data I discuss in Chapter 6 when participants talk about '*the hard evidence*' provided by their test results, ranking these above feelings of illness or wellness as a way of assessing their state of health. A closely related hierarchy underpins the stance Kelly et al identify as still prevalent in the biomedical community, informing the characterisation of 'robust scientific evidence' as a stable, value neutral entity divorced from 'social, economic, and/or political circumstances'. Like Kelly et al, Lambert, Gordon and Bogdan Lovis [2006] problematise the tacit norms and assumptions that make sense of this stance, foregrounding various vested interests that support a preference for certain types of research question and, relatedly, for the methodological approaches best suited to answering such questions. Greenhalgh et al address these concerns in their recommendations: they call for increased transparency, at least regarding commercial vested interests, and for a 'broader and more interdisciplinary' research agenda. This agenda should, for instance, 'embrace the experience of illness', an aim only likely to be achieved by doing some qualitative research. An increased respect for the contribution of qualitative research is one of two key features that distinguish 'real' from traditional EBM. The other salient distinguishing feature is that real EBM adopts a greatly expanded remit, broadening its focus to give as much attention to the way evidence gets used as to the way it gets generated.

### ***Using evidence: ethical dimensions***

In her essay about ethical aspects of EBM, Gupta [2011] traces a shift over time away from the original framing of EBM as an enterprise primarily concerned with evidence



generation. 'Dissemination of evidence' is identified as an objective of EBM in this earlier iteration, but, once disseminated, the way evidence gets used is implicitly beyond the remit of the 'traditional' EBM project. Greenhalgh et al's recommendations for the new, improved 'real EBM' begin by raising the prominence of its 'dissemination' aspect, recognising the need to strengthen a reciprocity of influence between evidence generation and evidence use. In the traditional model, evidence is generated by academics and then handed to practitioners to use, whereas in real EBM, the requirements and preferences of users (both health professionals and patients) informs the process of evidence generation. In addition, real EBM broadens the remit of evidence generation to include evidence use as an object of study in itself. By foregrounding objects like 'a strong clinician patient relationship', 'the human aspects of care', and 'meaningful conversations' with patients, real EBM implicitly positions itself as part of what Kelly et al term 'the recent backlash against EBM ... on the grounds that the slavish following of "evidence based" guidelines poses threats to patients'. Greenhalgh et al describe these grounds in more temperate terms: 'Inflexible rules and technology driven prompts may produce care that is management driven rather than patient centred'. This formulation implies that 'management' and 'patient centred' goals are likely to drive care in opposite directions, and that the authors' preference is for the patient centred direction.

By casting what they term 'the human aspects of care' as one of the key priorities of real EBM, Greenhalgh et al tacitly lay claim to the moral high ground of providing 'ethical care'. But this claim is open to challenge, as is illustrated by Summerskill and Pope's [2002] account of the way doctors talk about offering preventive medication, an account that emphasises the benefits of such medication, describing it as 'potentially life-saving'. Summerskill and Pope demote their doctor participants' 'desire to preserve a good relationship' to at best an equal ranking with the goal of 'implementing evidence', and comment that 'the doctor: patient relationship may act as barrier to the delivery of ... appropriate secondary prevention'. To overcome this barrier, the authors suggest moving the task of offering statins away from doctors, replacing GP consultations about prevention with 'nurse-led, protocol-driven clinics'. Bracketing the questionable assumption that nurses do simply follow protocols (an assumption challenged, for instance, by Boase et al's [2012] account of the way nurses practise cardiovascular risk communication), this approach is clearly at odds with the discourses

informing real EBM: Greenhalgh et al recommend moving away from ‘overemphasis on following algorithmic rules’ towards ‘expert judgment’ used in the context of ‘a strong interpersonal relationship between patient and clinician’. In contrast, Summerskill and Pope’s account is informed by a discourse Kelly et al identify as informing early iterations of EBM, that ‘using unbiased evidence was by definition beneficent...[and] to do anything other than EBM [was] tantamount to maleficence’; when one of Summerskill and Pope’s participants decides to avoid worrying a patient with unsolicited offers of statins or aspirin, so as to preserve their good relationship, they stand accused of neglecting the best interests of that patient by failing to encourage her to take evidence based preventive medication.

These two approaches, then, are informed by two contrasting priorities, one favouring ‘the human aspects of care’, the other favouring a reduction in the risk of future illness. Gupta’s [2011] account sheds some light on this contrast; she describes a shift since EBM’s inception from improved health towards shared decision making as its central goal, and emphasises that, just as Summerskill and Pope’s research demonstrates, these two goals are often in tension. The root of this tension is that, both within a clinical encounter and in the context of health policy decisions, people who are able to take evidence-informed decisions often make choices at odds with the evidence; they may prefer to take antibiotics for their sore throat or to keep their small local hospital open, or may decline the offer of statins. Within research and debate about shared decision making, early assumptions that a fully evidence-informed decision would inevitably be a decision in line with the evidence have long been put aside in favour of a more inward facing set of goals for shared decision making. Writing about what constitutes good decision making, for example, Elwyn and Miron-Schatz [2009] make this shift explicit, stating that ‘decisions cannot be measured by reference to their outcomes’ but only by assessing the decision making process itself.

Kelly et al identify a further salient tension regarding the goals of EBM, a potential conflict between ‘the best interests of the patient’ and the best interests of the population. Heath, one of Kelly’s co-authors, makes an explicit plea [2003] for ranking individual above population interests. Her essay challenges the claim that shifting the aim of medication policies from compliance to concordance represents a significant ethical advance. Heath expresses a strong preference for clinical approaches that respect ‘the dignity and autonomy of each patient’ over those that prioritise ‘following

recommended medical guidance'. As Summerskill and Pope imply, however, a patient might prioritise being offered recommended medical guidance over having their dignity and autonomy respected, if these two priorities compete. Heath does present them as competing options, representing the tension between them as a manifestation of the 'familiar conflict between the utilitarian benefit of the many and the dignity and freedom of the individual' and casting a preference for utilitarianism as a step towards coercion and tyranny. In Kelly et al's account, however, this stance is itself problematised in a discussion of the articulations between utilitarianism and equity, and of the instability inherent in notions of equity and efficiency; cost effectiveness, an attribute the authors identify as central to the EBM project, rests on value judgements about what a given effect is worth. Thus, however carefully the size and likelihood of an effect are calculated, its worth is inevitably context dependent and therefore irreducibly value laden, very liable to be contested. Specifically, an EBM shaped by heeding 'patients'' preferences may well differ significantly from one shaped by heeding the preferences of the citizens or tax payers who fund healthcare in the UK.

The potential conflict between different stakeholders' preferences is often visible in relation to patient groups convened around a particular disease; this is illustrated, for example, by the preferences expressed by cancer patients and their relatives in favour of the provision of treatments deemed insufficiently cost effective by the healthcare provider. A similar conflict, slightly less easy to see but more relevant to my argument here, is enacted within a clinical consultation and also within the policy making process that determines how long consultations last and how easily the system offers continuity of care. Both at the clinical practice level and the policy making level, this conflict has two overlapping dimensions: the time available for a consultation, and the style and focus of that consultation. Kelly et al highlight clinicians' time as a key resource liable to be constrained and therefore competed for. Using as an example the recommendation to offer statins to a larger group of people, they point out that 'one evidence based recommendation that generates large amounts of work for clinicians inevitably threatens other evidence based interventions, since there is only a finite number of hours in the day'. Thus clinicians have to choose between different evidence based recommendations, unless those who pay them decide to pay for more of their time.

The second choice that clinicians and healthcare providers have to make is the more complicated one indicated by Summerskill and Pope's [2002] discussion. This choice

concerns the style of the consultation: is the clinician to focus primarily on facilitating the ‘meaningful conversations’ through which Greenhalgh et al propose that they should carry on real EBM, or to focus on implementing ‘potentially life-saving’ evidence based recommendations? My research question was prompted by experiential knowledge of the difficulty of maintaining a dual focus, and of the impossibility of doing so within a ten minute consultation. At a policy making level, too, those who organise clinical provision have to address this dimension of clinical care and decide how much to pay for particular style features; providing longer, less rushed consultations, or else enough clinical capacity to facilitate continuity for a patient to see the same GP for successive instalments of their meaningful conversation, are both expensive interventions [Polak 2013]. The nurse-led clinics through which Summerskill and Pope propose to improve evidence implementation, shaped by protocols or decision aids, are cheaper, but offering these clinics alongside consultations with a familiar GP, in the way that Summerskill and Pope suggest, constitutes an additional expense. The salience of cost is highlighted by Rees Jones et al [2004] in their study of decision-making in UK primary care. Looking at the way scarcity of resources shapes patient involvement, they emphasise that ‘greater patient involvement’ has financial implications, not only because patients may make expensive choices but also because of the cost of ‘addressing the demands made on consultation time’.

Different ways of using clinical consultations, then, compete for the same expensive resource. Kelly et al raise interesting questions about which group of stakeholders should be allowed to decide how to rank the competitors. These questions apply not only to choices between different evidence based interventions but also to choices about the style of the consultation; taxpayers who seldom need or want to see a GP may prefer not to allocate resources to making meaningful conversations possible for those people who consult more frequently. Greenhalgh et al’s statement, that the key aim of real EBM is to ensure ‘that individual patients get optimal treatment’, sidesteps questions about the way power is or should be allocated to stakeholders who compete to determine resource allocation. Yet placing the individual patient centre stage is in itself a normative move, underpinned by moral discourses about respecting individual dignity and autonomy. This move is complicated by the difficulty of defining ‘a patient’ in the context of the increasing prevalence of ‘chronic conditions’, a category whose boundaries are increasingly fuzzy; I discuss this fuzziness in Chapter 4, foregrounding

the salience of time as a dimension of ‘having a condition’. For the argument in this chapter, I shall define a patient in a context-dependent way, as a person who is currently consulting a clinician. I now turn my attention to the way clinical consultations may be informed by both quantitative and qualitative research findings, using my own qualitative findings as an example. Having considered the various ways in which the ‘goodness’ of care may be evaluated, this concluding section of the thesis explores the role of evidence in the everyday delivery of good care.

### **Providing ‘good care’: using research evidence in everyday clinical practice**

In this final section of the chapter I explore the ways in which a clinician’s job is informed by various kinds of theoretical knowledge derived from research, the knowledge that constitutes ‘evidence’ in the context of discussions of EBM. In this exploration I draw on Annemarie Mol’s (2008) ethnographic study of what goes on in a hospital clinic caring for people with diabetes. Mol frames her book as an account of what she calls the logic or rationale of care, a collection of tacit ‘rules’ and discourses that delineate and inform the group of practices through which care is enacted. Using the logic of care as an example of the kind of object that they would like to see elucidated by qualitative research, Greenhalgh et al describe it as ‘the numerous elements of good illness management that are complementary to the application of research evidence’. This formulation tacitly equates ‘research evidence’ with quantitative research evidence, with qualitative evidence cast as an accessory. Instead, I argue for a shift of perspective that portrays these two different kinds of ‘research evidence’ as sharing the stage, casting both kinds as essential constituents of EBM: without qualitative research evidence about the way quantitative findings get used in practice, the potential beneficial impact of those quantitative findings cannot be realised. In this portrayal, then, qualitative evidence does indeed complement quantitative evidence, but not in the supporting role implicit in Greenhalgh et al’s recommendation.

This point builds on Green and Britten’s [1998] discussion of the relationship between qualitative research and ‘scientific evidence’. Writing long before the assumption that EBM simply concerned quantitative evidence began to be questioned, Green and Britten state that ‘recognising the limits of evidence based medicine does not imply a rejection of research evidence but awareness that different research questions require different kinds of research’. Greenhalgh et al’s proposals effectively expand this statement: in its

renaissance, EBM is to extend beyond its old limits, explicitly embracing ‘a broader research agenda’. Yet this embrace does not necessarily confer parity of esteem between different items on the agenda or between the different kinds of research needed to address them. I argue here that if EBM is to concern itself not only with the generation of evidence but also with the way evidence gets used in practice, as the exponents of real EBM recommend, then it must move away from assumptions that rank quantitative above qualitative evidence as a way to describe the world and inform action. To support this move, I present an account of the way qualitative and quantitative research articulate to shape the practices through which clinicians enact patient care; I illustrate this account by drawing on my own qualitative research findings, as well as on my experience of working as a clinician and running a practice.

### *Using qualitative and quantitative evidence*

The puzzle that inspired my research arose from the knowledge that, at least as a way of implementing the extensive quantitative research evidence about statins, my clinical consultations were not very cost effective: spending a lot of expensive time and effort helping each patient make an evidence-informed decision in accord with their own medical and personal circumstances has a relatively low yield in terms of people taking statins for years after the consultation. This puzzle can be understood in terms of the two possible goals of EBM that Gupta [2011] identifies; my consultations seem more successful as a means of facilitating shared decision making than as a means of improving population health. The pursuit of these goals maps roughly onto the two different jobs I do as a GP in the UK National Health Service: facilitating shared decision making predominates as the goal of everyday clinical practice, while improving population health is the primary goal of the policy making and management work required to run a very stretched primary care service.

It is easy to find examples within this thesis to support the claim that qualitative research informs everyday clinical practice. The findings presented in Chapters 3 and 4, for instance, raise questions about assumptions that underpin the enterprise of risk communication, challenging the value of goals that include increasing ‘the accuracy of risk perception’ [Trevena 2014]. In Chapter 4 I also explore the way ‘need’ is constituted in the context of preventive medication, and the irreducibly slippery distinction between treating a current problem and preventing a future one. This exploration raises questions about how to define ‘a patient’, and highlights the insight,

novel to a member of the biomedical community, that ‘prevention’ is not widely equated with ‘risk reduction’ outside that community. Together with the account in Chapter 5 that frames taking statins as a threat to a presentable identity, these findings inform both the content and style of my clinical practice; they shift my focus away from presenting people with ‘individualised evidence in a format that ... patients can understand’ as Greenhalgh et al recommend. Instead, I relegate the individualised evidence to a supporting and optional role within the story the patient and I co-construct about the best thing to do, a story whose essential characteristic is certainty. In Chapter 6, I cast this story as a decision, offering an account that frames its co-construction as one of a collection of discursively informed social practices that constitutes a clinical consultation. This framing changes my consultation goals, rearranging them in relation to one another. The rearrangement involves prioritising ‘meaningful conversations’, as advocated by Greenhalgh et al, but this move does not simply displace the two standard consultation goals of facilitating shared decision making and implementing quantitative evidence. Instead, both these goals remain highly salient but are reconceptualised, while the meaningful conversation is valuable not only in its own right (a value derived from some of the ethical preferences discussed earlier) but also as a means to several ends, including an evidence-informed decision.

These examples illustrate that qualitative research sheds a useful light on the practices that constitute a clinical encounter, a light that has the potential to shape such encounters so as to further several widely accepted goals like an evidence-informed decision and a meaningful conversation. This effect on everyday clinical practice produces a secondary effect through which my findings also influence health policy making. In my own management role, having to put a price on facilitating continuity of care, I have been influenced by the model of decision making presented in Chapter 6. This model implies that, at least in the context of considering longterm medication, continuity is worth buying because it is a precondition for useful consultations: a brief one off encounter makes it impossible for the clinician and the patient to co-construct a story that articulates with the web of discourses and interactions through which regular pill taking is carried on.

By maximising the time available for health-improving work, choosing between competing uses of clinicians’ time contributes to improving population health, and hence evidence that informs such choosing can be seen as furthering one of the key

goals of EBM. However, this goal of population health improvement is often construed more narrowly, as Summerskill and Pope illustrate in their focus on implementing ‘potentially life-saving evidence’. The story in Chapters 5 and 6 raises questions about the extent to which implementation can be achieved within a clinical encounter. This story complicates accounts that separate deciding about pill taking from enacting it, and that portray the two as related through a simple one-way causal link. By replacing it with a more complex story about the extensive web of interactions and practices through which decisions are produced and regular longterm pill taking is enacted, I make it impossible to trace a tidy causal path linking an evidence-informed (or even an evidence based) decision in the consulting room to regular longterm pill taking. Because quantitative evidence suggests that such pill taking improves population health, the most highly valued goal of many biomedical recommendations is a strong link between what goes on in a clinical encounter and regular pill taking – specifically, a link that increases the likelihood of ‘adherence’ to the plans agreed within clinical consultations. Weakening that causal link complicates the definition of what Summerskill and Pope [2002] describe as ‘implementing the evidence’. Because their research concerns GP consultations, it is beyond their remit to consider the extent to which recommending medication (either within these consultations or in ‘nurse-led, protocol-driven clinics’) is successful in terms of people actually taking the pills regularly at home over many years. This longterm pill taking is the primary end point of ‘implementing’ the evidence that says such medication is beneficial.

Early in my research, one of my aims was to complement Summerskill and Pope’s findings, and I initially adopted their implicit framing, defining success as an increase in adherence; I set out to interview people at home in the hope of shedding some light on the well established low success rate of advising individual patients to take statins. Problematising the biomedically rooted assumptions that make sense of this framing led me to abandon it, but my findings do nonetheless have implications for practitioners seeking to improve population health by implementing evidence about preventive medication. The account in Chapter 6 portrays longterm pill taking as carried on within a broad web of social practices that includes clinical encounters but does not centre on them. This implies that quantitative evidence about statins, for example, cannot simply be ‘implemented’ by a clinician, however driven they are by protocols; regarding ‘the [quantitative] evidence’, all the clinician can hope to achieve is a meaningful



conversation through which the patient constructs an evidence-informed story about the right thing to do, a story that may contribute to what they end up doing about the pills elsewhere and at other times. This conversation is a central constituent of the collection of practices through which a clinician provides care to an individual patient, a collection of practices that is shaped by the logic of care; it is this logic that Summerskill and Pope's GP participants surface in talking about their consultations, implicitly favouring it over the logic of choice. To understand the relationship between these two logics I draw on Mol's account of them, using it to consider the way using evidence articulates with other elements of clinical care.

***The logic of care: how caring is done, and who does it.***

Mol's account of the logic of care [2008] sits comfortably both with my research findings and with my experiential knowledge about offering preventive medication within GP consultations. One of Mol's central points, drawing on her ethnographic findings, is that clinicians tend to follow the logic of care rather than the logic of choice. She contrasts these two logics and suggests that, where they are both used at once, incompatibilities between them get resolved by tacitly allowing one set of rules to trump the other. In an example drawn from her own experience, for instance, a nurse involved in a frightening medical procedure acts in accordance to the logic of choice in such a way as to contravene rules fundamental to the logic of care: in response to her patient's anxious question 'she snaps back "Well it is your own choice."' Suggesting that 'there is an element of trickery in the logic of choice', Kelly [2009] identifies a parallel between Mol's story and the findings of a study in which women with breast cancer 'talk about "blame" for making the wrong decision'; she highlights the need to recognise that while choice is often portrayed as conferring power, it also carries a burden of responsibility.

My own account builds on Mol's exploration of 'what happens when [the logic of choice and the logic of care] get mixed together – as they do in real life' [p96]; she relegates choice to a subsidiary role, casting it as one constituent of a collection of practices informed by the logic of care. Within this collection of practices it is possible (but not essential) to create 'situations of choice', situations exemplified by consultations where the patient chooses to engage with discussion of their risk estimate and then uses that quantitative information to inform their medication practices. Thus Mol's account provides a helpful clarity, situating 'choosing' in relation to a broad web

of multiple practices of care, in a way very similar to the way I position the cognitive work of decision making in the paper in Chapter 6 as entangled within a web of tacit discourses and everyday medication practices. Both accounts emphasise that the constituents of the web include interactions with many different people and technologies, enacted in a variety of different times and places and shaped by multiple and often conflicting discourses.

Both Mol's account and my similar one provide a way of thinking about the various different elements of Greenhalgh et al's model of real EBM, a way of ordering those elements in relation to one another. Some elements make sense only as constituents of a group of practices that is primarily underpinned by the logic of choice, and predominantly informed by quantitative evidence. Greenhalgh et al call for transparency about commercial vested interests involved in generating evidence, for instance, and for a range of formats (such as 'infographics, option grids, and... decision aids') for presenting that evidence to its users; these are subsidiary goals of a group of practices whose key product is a rational choice between options derived from trustworthy information about large populations. Other elements of real EBM in Greenhalgh et al's account, however, suggest that this evidence-based choosing is to be enacted within a clinical approach centred on care: real EBM 'builds on a strong clinician patient relationship and the human aspects of care', for example. Rather than just listing all these disparate elements together, my account builds on Mol's to frame choice itself as a potential but inessential product of a group of practices that is informed by the logic of care.

By describing what is going on in terms of social practices, this account addresses two closely interconnected questions that are beyond the remit of Greenhalgh et al's essay but highly pertinent to it: how is care to be defined, and who does it? Greenhalgh et al define the logic of care as 'the numerous elements of good illness management', and place the wish to ensure 'that individual patients get optimal treatment' at the top of their list of the goals of real EBM. These phrases surface assumptions that care can be understood as managing or treating an illness, and hence that it is something that is done by clinicians to ill people or 'patients' – the widespread use of 'self-management' and 'self-treatment', to identify an atypical usage that refers to things people do for themselves, surfaces the tacit perception that 'management' and 'treatment' are things

clinicians do to patients. Such assumptions are not very helpful for understanding how people come to take statins at home, over many years, while they are well.

My alternative approach complements and refines the real EBM model by rearranging its constituents, rather than by proposing to remove any of them: the practices through which a clinician treats or manages a patient's illness are situated within a web of care practices, a collection of distributed practices involved in health care, and this collection itself sits within a broader web of practices through which everyday life is carried on. Caring is enacted throughout these inextricably entangled webs of practices; the articulations between the various elements are shaped by discourses that are integral constituents of the logic of care. This account highlights collaboration as an indispensable element of medication practices, and situates collaborating with clinicians as just one of many salient kinds of interaction. The resulting complex, untidy model offers a far better fit with my data than widely-implicit models in which decisions about treatment and management are made during clinical consultations and then enacted at home; these tidy linear models, featuring a one way articulation between deciding and doing, may help account for decisions about one-off medical interventions but are less helpful for understanding how people come to take longterm medication.

Mol's care-centred framing is particularly helpful for constructing a plausible story in this thesis about how people come to take regular medication while they feel well, a story that makes sense both of my findings and of my clinical experience. Although the opening sentence of her book presents the book's central topic as 'dealing with disease', suggesting a focus similar to Greenhalgh et al's 'illness management', Mol goes on explicitly to challenge the feasibility of drawing a clear distinction between people with a disease and healthy people, and to emphasise that dealing with disease is shared work that requires collaboration between patients and clinicians. Her observation of clinical encounters generates data about the negotiation and compromise these encounters involve and the various different lines of work being carried on; in this respect, her account is similar to the one I offer in the paper in Chapter 5, where I describe the complex calibration processes my participants use to resolve tensions between conflicting norms about collecting information, taking medication, and seeking and heeding medical advice.

At a more theoretical level, Mol offers a useful discussion of the shared and shifting character of agency (pp107-108), and problematises the valorisation of autonomy that is widely visible both in writings about health policy and in the documents that set it out. I draw on this discussion in the paper in Chapter 6, where I consider the limitations of ‘autonomy’ as a concept for explaining how people come to take regular medication, and propose that ‘relational agency’ is a more useful concept for this purpose. Knocking the idea of autonomy off its pedestal in this way has the potential to disrupt discourses that shape healthcare at many levels, raising questions about other widely valorised concepts such as patient empowerment and self care, and challenging the increasing move to direct clinicians’ energies towards ensuring that patients have all the information they need to make choices. Back in the GP consulting room where I began this thesis, the impact of a shift from the logic of choice to the logic of care may be blunted by the fact that the tacit discourses that have always shaped clinical practice are rooted in the logic of care rather than the logic of choice; one of the most useful aspects of Greenhalgh et al’s account of real EBM is the legitimacy it confers on ‘a strong clinician-patient relationship and the human aspects of care’ as fundamental to the job clinicians do.

## **Conclusion**

The story told in this thesis does more than it set out to do. At its core, in Chapters 3- 6, I present and discuss findings about the way people who have been offered statins come either to take or not to take them. These chapters and the papers incorporated within them provide an account that answers the question I posed before beginning the research: How do people make up their minds about statins? The limitations of this initial question became apparent during the research process, leading me to broaden my focus. The question I have ended up addressing, about the way people come to take or to decline statins, subsumes the earlier, narrower question rather than replacing it. The best fit with the empirical data turns out to be a story about the complex web of discursively informed social practices through which regular pill taking is enacted.

In Chapters 7 and 8, I use the empirically grounded core provided by the earlier chapters as the starting point for contributions to two different areas of theoretical debate. Chapter 7 builds on two ideas, one about e-scaped medicine and the other about the nature of expertise, to produce an account of the way knowledge about health is

constructed and used. Finally, here in Chapter 8, I use this understanding of knowledge construction to consider the particular collection of theoretical knowledge we call evidence: I begin by examining the practical and ethical considerations that shape both the generation of evidence and its use in clinical practice, and then situate evidence use within a group of practices informed by the normative discourses that delineate ‘good care’. Thus the story brings me back to where I began, in a clinical consulting room where my job is primarily about providing care to the individual in front of me.

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## Appendix A: Tools for interviewing

This appendix presents the topic guide I started out with, intending to use it within semi-structured interviews. As discussed in Chapter 2, I moved to a more narrative interviewing style after the first few interviews, and used fewer and fewer of the questions on the topic guide. However, as the participant information leaflet on the next page shows, all participants were aware that “how they decided about statins” was the central focus of my enquiries.

### Topic guide:

1. General state of health –
  - Pills – including vitamins etc
  - When did you last go to the surgery? Can you tell me a bit about that?
  - Compared to other people your age, how would you describe your health?
2. Statins –
  - First suggestion: what did you already know? How? Did you know other people on them? How did you come to be having that conversation with the doctor/nurse? What did they say?
  - What was your reaction?
  - Then what, after leaving the surgery after that conversation?
  - & since then? now? Taking regularly? Issues/ problems?
3. Keeping healthy –
  - Worries about health –now? – future?
  - Do you think about doing anything particular to keep yourself healthy?
  - Do you tend to read stuff about health issues, watch it on TV etc? tell about that.

### Questionnaire at end (background info)

- d.o.b
- Have you had any serious health problems? – specify:
  - heart problems [IHD unless noted otherwise]
  - a stroke
  - diabetes

- kidney problems
  - problems with circulation in your legs
- Is there any history of heart problems or strokes among your close relatives?
- Do you smoke? Did you? [approximate numbers/ dates]
- What is/ was your job?

## **Participant information leaflet:**

### **A study looking at patients' views about statins: some information to help you decide whether to take part.**

#### **What the study is about, and why it is important**

This study is about how people make up their minds about statins.

Not everyone who is offered a statin by their doctor decides to take it.

There may be lots of reasons for this, but we do not know which ones are most important.

Finding out what you think about this will be very useful, so that we can tell doctors what information helps people to make a decision that is right for them.

After doing the interviews and comparing the different answers, I shall be looking for patterns in what people say, to try to work out what most people think and how they decide whether to go on taking statins.

#### **Who is doing the study**

My name is Louisa Polak, and I am doing this research with support from LSHTM, a part of London University.

I can be contacted there: [Louisa.Polak@lshtm.ac.uk](mailto:Louisa.Polak@lshtm.ac.uk).

My phone numbers are 01206 272372 and 07796 368390

#### **What this study will involve for you, if you decide to take part**

##### **A. Agreeing to take part**

If you would rather **not** take part, please just let me know.

If you think you might be willing to be interviewed, you do not need to do anything: if you have not contacted me after a few days then I will ring you to see whether you need to ask me any questions before making up your mind.

If you do decide to go ahead, then we can make an appointment at a place and time that suits you. But if you change your mind at any stage, even after the end of the interview, just tell me and I shall not use anything you have said.

## **B. Interviews**

You will choose where and when to be interviewed. I cannot pay you but will bring tea and biscuits!

To find out what you think about statins I shall be asking you a few questions.

These will take about 40 minutes to talk through.

I would like to use a tape recorder, to remind me exactly what we said, but if this bothers you I could just make some written notes instead.

If you would like a relative or friend to be present while we are talking, they would be very welcome, and if they are someone who you tend to talk to about your medication then I should be interested to collect their views as well as yours.

## **C. Confidentiality**

I hope to end up with some interesting answers to my questions, and will want to discuss them with colleagues and perhaps to write something about them, but in writing or discussion I will never refer to you by name: nobody will be able to tell who gave me which answer.

This includes your own doctor.

If you are not happy to be quoted anonymously in this way, you can just say so. Before we begin I shall be asking you to sign a consent form, and it includes a box we can tick about this.

You can also change your mind after the interview.

**Any questions?**

If you think of any more questions in the meantime, I shall be happy to answer them before we begin, or else you are welcome to contact me for a chat before the appointment.

**Thank you for taking the time to read this.**



## Consent Form:

Study title:

Taking pills for prevention: a qualitative study.

Researcher: Louisa Polak

telephone: 01206 272372

email: Louisa.Polak@lshtm.ac.uk

1. I have read the information sheet concerning this study and I understand what will be required of me and what will happen if I take part in it.
2. My questions concerning this study have been answered by Dr Polak
3. I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.
4. I agree to take part in this study.
5. I agree to quotations from my interview being included anonymously in reports about the study\*.

Signed ..... Date .....

\*Please delete this if you are NOT happy to be quoted (anonymously)

## Appendix B: Information about interviewees

**Phase 1: participants recruited by snowballing from personal acquaintances:  
people taking statins, and their significant others**

<b>name</b>	<b>age</b>	<b>occupation</b>	<b>on statins<sup>i</sup></b>	<b>heart attack<sup>ii</sup></b>	<b>couple interview</b>
Alan	57	university lecturer	yes	no	no
Bill	58	engineer	no	no	no
Ann	83	housewife	yes	yes	yes
Colin	79	bow maker	yes	yes	yes
Don	66	physics teacher	yes	no	yes
Ed	67	art teacher	no	no	no
Frank	82	journalist	yes	yes	yes
Barbara	62	singer	yes	no	yes
Geoff	53	musician	yes	no	no
Henry	74	civil servant	yes	no	yes
Liz	72	music teacher	no	no	yes
Ian	57	GP	no	no	no

**Phase 2: participants recruited at a local activity programme, to which people get directed after completing cardiac rehabilitation after a heart attack**

<b>name</b>	<b>age</b>	<b>occupation</b>	<b>on statins</b>	<b>heart attack</b>	<b>couple interview</b>
Claire	67	telephonist	yes	yes	yes
Walter		<i>missing</i>	no	no	yes
Jim	79	plumber	yes	yes	yes
Violet		<i>missing</i>	no	no	yes
Keith	65	bank manager	yes	yes	yes
Debbie	66	GP receptionist	no	no	yes
Larry	62	carpet cleaning	yes	yes	no
Mike	74	dock worker	yes	yes	yes
Eileen		<i>missing</i>	yes	no	yes
Neil	66	office work	yes	yes	no
Peter	65	police	yes	yes	yes
Wendy		<i>missing</i>	no	no	yes
Ron	73	football coach	yes	yes	yes
Fiona		foster carer	no	no	yes
Simon	72	tube manager	yes	yes	yes
Gill	68	clerk	no	no	yes
Ted	69	insurance	yes	yes	yes
Hazel	61	vicar	no	no	yes
Vic	69	company manager	yes	yes	yes
Janet	69	<i>missing</i>	no	no	yes

**Phase 3: participants recruited at a lunch club held on a large council housing estate**

<b>name</b>	<b>age</b>	<b>occupation</b>	<b>on statins</b>	<b>heart attack</b>	<b>couple interview</b>
Will	58	never employed	yes	no	yes
Susan		never employed	yes	no	yes
Kathy	68	coach driver	yes	no	no
Lorna	63	cashier	no	no	no
Mavis	87	nurse	yes	yes	no
Arthur	71	technician	yes	no	no

**Phase 4: participants recruited via a message sent to all my colleagues, asking them to suggest friends and relatives who were not taking statins although they had had a heart attack**

<b>name</b>	<b>age</b>	<b>occupation</b>	<b>on statins</b>	<b>heart attack</b>	<b>couple interview</b>
Bert	84	farmer	no	yes	no
Chris	73	printer	no	yes	yes
Yvonne	71	nurse	no	no	yes
David	64	bank clerk	yes	no	yes
Julie	59	cleaning	no	no	yes

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<sup>i</sup> The “on statins” column identifies participants who said they were taking statins at the time they were interviewed.

<sup>ii</sup> The “heart attack” column identifies people who said they had had a heart attack or an emergency admission to hospital for heart treatment; in Chapter 2, I discuss the loose relationship between this parameter and the “primary/ secondary prevention” distinction used in biomedical writings and practice.