Overruling uncertainty about preventative medications: the social organisation of healthcare professionals' knowledge and practices

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Abstract   In this article, we draw on an institutional ethnographic (IE) study of cardiovascular disease prevention in general practice, exploring the work of healthcare professionals who introduce a discussion of risk and preventative medications into consultations with patients. Our aim is to explicate, using IE's theoretical ontology and analytical tools, how troubling patient experiences in this clinical context are coordinated institutionally. We focus our attention on the social organisation of healthcare professionals' knowledge and front-line practices, highlighting the textual processes through which they overrule patients' concerns and uncertainties about taking preventative medication, such that some patients feel unable to openly discuss their health needs in preventative consultations. We show how healthcare professionals activate knowledge of 'evidence-based risk reduction' to frame patients' queries as 'barriers' to be overcome. Our analysis points not to deficiencies of healthcare professionals who lack the expertise or inclination to adequately 'share decisions' with patients, but to the ways in which their work is institutionally orientated towards performance measures which will demonstrate to local and national policymakers that they are tackling the 'burden of (cardiovascular) disease'.

Keywords: uncertainty, institutional ethnography, social organisation, cardiovascular disease prevention, performance measures, shared decision-making

Introduction

In England, as in other economically developed countries, prevention of cardiovascular disease (CVD) has become a policy priority (NHS England 2014, 2019). In response to newly available knowledge about the distribution of CVD and its risk factors from epidemiological research (e.g. Global Burden of Disease project (Lopez *et al.* 2006)), policymakers have developed a suite of interventions aiming to reduce CVD mortality and morbidity (Public Health England 2016a). Such interventions have become established through their inclusion in evidence-based clinical guidelines for healthcare professionals (HCPs) working in general

practice. They are not only calculated to improve population-level health outcomes but also to be highly cost-effective. In particular, the pharmaceutical treatment of 'risk conditions' (e.g. hypertension, Type 2 Diabetes Mellitus and hypercholesterolaemia) is projected to accrue significant future healthcare savings (Kearney and Freeman 2016) by preventing or delaying disease onset. The NHS Health Check programme has been developed to support the preventative agenda through the identification and treatment of both risk conditions and lifestyle risk factors (Public Health England 2016b).

Using institutional ethnography (IE) (Smith 2005), we explicate CVD prevention as a 'sphere of activity' (Smith 2014: 227) that is institutionally coordinated by people working at the local, national and international level, and that is embedded within the Global Burden of Disease (GBD) discourse. In IE, 'discourse' encompasses texts, talk and activity–and is understood to be a central feature of ruling practice. Its peculiarity is the way that the talk and activity of those 'who claim membership' of it, (ibid. p.229), becomes (at least to a degree) 'standardised' (ibid. p.231). Within GBD discourse, talk and activity is coordinated through epidemiological metrics, and through the statistical outcomes of clinical trials which inform 'evidence-based medicine' (EBM). As Adams (2016) writes in her critical analysis of 'global health', such 'technologies of counting [...] are imagined to offer uniform and standardised conversations about how best to intervene, how best to conceptualise health and disease, how best to both count and be accountable, and how best to pay for it all' (ibid., p.6). GBD metrics in particular add a highly visible and simplified overlay to what Mykhalovskiy (2001) has, in a similar vein, called the 'patterned universe' of health services research. A small range of performance indicators, representing seemingly neutral accounts of the 'real world' (yet laced with all kinds of politics and managerial imperatives relating to 'efficiency' and cost savings), are given prominence within GBD discourse.

Drawing on an IE of CVD prevention in general practice (Cupit 2018), we examine how socially organised practices of knowledge known as CVD prevention enter the work of HCPs, and thus the work of patients. We point to the complex, constructed nature of 'risk', focusing on how HCPs *utilise* risk-scoring technology (Hippisley-Cox *et al.* 2010, Will 2005)–which has become central to informing statin-based treatment across populations, and a key component of economic models for prevention. We show how risk scoring is being employed in HCPs' practice (in the context of Health Checks)–and how this work intersects with, and shapes, patients' knowledge and uncertainties about how to improve their health. We explore how the 'best' science, generated systematically from huge epidemiological datasets, large controlled studies, the aggregates of systematic reviews and economic forecasting, actually plays out in the everyday world of health care. Crucially, we show how the *form of knowledge* embedded in the texts and activities of CVD prevention creates a tension for practitioners and patients–those people whose own knowledge 'bumps into' such tidy numerical abstractions. Statistical generalisations enter a 'ruling relation' (Smith 1987: 3) into the subjectivities and uncertainties of their day-to-day prevention work. Our aim is to show empirically how clinicians and patients' *knowledgeable actions* (and the embedded elements of *uncertainty* that underpin each encounter) are socially organised within the relations of GBD and evidence-based risk management discourse.

We understand 'uncertainty' to be an integral part of the experience of both HCPs and patients and therefore an inevitable feature of front-line clinical practice. Patients bring the many 'viscous variables' of their lives (Mol 2008: 62) to a clinical encounter, and HCPs are tasked with responding to these, bringing not only their evidence-based clinical knowledge but also their 'tacit, context-bound and ephemeral' knowledge (Greenhalgh 2013). Employing IE's theoretical framework, our conceptualisation of 'uncertainty' is allied to *knowledge*–a key analytical focus of IE. Patients bring their local knowledge (and uncertainties) of what can be

done to improve health, the experiences of trying to break unhealthy habits and the many aspects of everyday life which intersect with these experiences; HCPs bring their own local knowledge (and uncertainties) about how they can best support patients' work to improve their health. 'Good care' involves HCPs and patients working together to 'try, adjust, and try again' in the light of the many variables, uncertainties and what is possible and/or desirable in the circumstances (Mol 2008: 22).

The research reported here builds an account of how risk scoring enters front-line consultations and how it shapes decisions about preventative action–and particularly decision-making about statins. Our analysis, focused on explicating the *organisation* behind HCPs' work (in the context of decisions about statins), extends the insights of Mol (2008). We explicate how the work of trying, adjusting and trying again is organised to happen (or not), examining the socially organised circumstances of everyday practice that shape what is possible. Our analysis adds to the findings of Polak (2016), who explored patients' (un)certainty in relation to statin decisions. It exposes the social organisation behind her intriguing finding that many patients were certain that statins were needed to treat *current* problems, even though they were actually treating *future* risk. It also elucidates the practices which result in patients seeing lifestyle change as 'futile' (Saukko *et al.* 2012). Additionally, our analysis complements other research that highlights the value patients place on HCPs' expertise–trusting them to provide personalised advice (see Will and Weiner 2015). Principally, however, our research responds to Mykhalovskiy and Weir's (2004) call for research investigating 'the specificity, discursive character and effects of EBM as a practice of knowledge' in its 'local and translocal dimensions'. We show how clinicians are *organised* to selectively activate ideas about evidence-based management of CVD risk, becoming preoccupied with ensuring that patients take up an offer of statin medication and neglecting behavioural support (even though this support is also emphasised in guidelines). We then expand our research gaze to identify the translocal dimensions of EBM and examine its 'specificity' as it arises as a 'practice of knowledge' (ibid.) designed to efficiently manage the innate uncertainty and unpredictability of each patient encounter. It is only when we redirect our gaze into dominant (ruling) relations that we see the social organisation of this preoccupation; we show how performance measures, orientated towards reducing the 'burden of disease' (in terms of lives and costs saved), are dominant organisers of HCPs' front-line work.

Institutional structures for CVD risk management with statin medications

In this section, we introduce the broad discursive terrain of evidence-based risk management as it arises in people's coordinated activities of risk scoring and discussions about preventative medications. Our presentation of various academic and other texts related to CVD risk (and the related topic of statin medications) is offered less as a 'literature review', and more as an analysis that seeks to make visible the component activities of CVD prevention–activities which are embedded in the work of people located throughout the broad institutional relations of CVD prevention.

One of the explicit goals of EBM is to reduce variation in clinical practice through the use of evidence-based clinical guidelines (Knaapen 2014, Timmermans and Berg 2010). The main guideline coordinating HCPs' work to score and manage an individual's 'overall risk' in English primary care is NICE guideline 'CG181' (NICE 2014a). Not only does a risk score quantify risk, it also forms the (textual) basis for offering statins (see Will 2005). Since 2009, risk scoring has been central to the NHS Health Check programme, providing a mechanism for identifying individuals at high CVD risk. Specifically, the Health Check is structured around a

prediction of an individual's chances of a heart attack or stroke over the following 10 years–calculated using 'QRISK' technology (Hippisley-Cox *et al.* 2010). To enable risk score calculation, the main NHS Health Check appointment (Part 1), usually delivered by a healthcare assistant, follows a structured sequence of questions and tests which capture the patient's basic demographic data, information about their 'lifestyle' and biological 'markers' including blood pressure, cholesterol and sugars (Public Health England 2016b). From this, a single risk score is produced, expressed as a percentage; CG181 recommends that patients with a risk score > 10% should be offered statins, and given guidance on healthy behaviours. The term '*offer*' indicates to HCPs that there is 'clear evidence of benefit' for the prescription of statins and this is a 'strong recommendation' (NICE 2014b)–reinforced within the Quality and Outcomes Framework financial incentive system (NHS Employers *et al.* 2015).

The risk score is usually calculated a few days after the main Health Check appointment, when blood test results become available, by a qualified nurse or a GP. This moment, when the risk score is calculated and high risk patients contacted (Part 2 of the check), is the point where we begin our explication of the institutional complexes that coordinate the administrative regime of CVD prevention practices; it is also where issues of certainty and uncertainty arise. The risk score brings GBD's statistical knowledge into the clinical encounter as a single text–a representation of the patient's various risk factors, calculated to guide action. The potential challenges of communicating statistical knowledge are recognised within the guideline, which includes many additional recommendations about how risk statistics should be communicated (e.g. using visual prompts).

There has been much debate about the benefits and harms of statins within clinical, academic, and (subsequently) public arenas. Some GP opinion leaders have, for example, proposed that HCPs who slavishly follow guidelines and the mathematical modelling of risk may be responsible for patients being 'over-treated' with statins (e.g. McCartney 2012, Price 2014). Fierce debate on the quality of the evidence for prophylactic use of statins in the pages of the *Lancet* and the *BMJ* was dubbed the 'statin wars' (Husten 2016). Campaigners have also highlighted that, for some patients, behavioural change may be a reasonable alternative to medications, and more in line with patient preferences (e.g. Unwin and Tobin 2015). Within this discursive terrain, although CG181 was developed in response to evidence about statins, it also strongly advocates both the promotion of behavioural change, and the principles of patient involvement, shared decision-making and patient-centred care–all of which emphasise the importance of patients' values and preferences in good-quality care. Ultimately, HCPs have to determine how to activate these parallel textual directions for both 'best treatment' and 'shared decision-making' in the complex world of patient care. And it is here, in clinical practices, where knowledge disjunctures arise–who knows what and whose knowledge 'rules'. It is this social organisation of decisions about statins which we examine more closely.

Methodology

This article draws on an IE of CVD prevention in general practice. Ethical approval was granted by the Liverpool NHS Research Ethics Committee (ref. 15/NW/0883). IE is an established 'mode of enquiry' (DeVault and McCoy 2006: 16) developed by Dorothy E Smith (1987, 2005). At its heart is a concern with the social organisation of people's knowledge and work. It is a method to investigate the ways people's *activities* (and *knowledge* of what to do) are coordinated by texts which embed interests generated at a distance from the local setting, often with troubling effects. These forms of coordination are reproduced repeatedly across different times and places (Smith 2005), often through textual technologies which allow particular

forms of knowledge to be standardised and spread from one location to another. The IE approach is particularly useful in revealing tensions between what is known from a local *experienced* position (known as a 'standpoint' in IE) and what is known from a translocal, ruling position (an *'institutional'* perspective). It is important to note here that the term 'institution' is not synonymous with 'organisation' in IE, but refers to 'processes that stretch across time and place to coordinate people's activities', which are interconnected around a specific function such as health care (Bisaillon 2012). The IE approach aims to map the tangible relations that establish how social settings are organised. In particular, an IE enquiry explicates 'ruling relations'–those practices that contribute to privilege or subjugation for those people for whom the research is conducted (the standpoint location). While not widely used within the sociology of health and illness, examples of IE in this field include studies of: the work involved in adhering to medication regimes (McCoy 2009); the use of research evidence within multidisciplinary teams (Quinlan 2009); and how electronic health records shape nursing work (Campbell and Rankin 2016).

The study contained multiple elements including: 24 interviews with patients who had at least one CVD 'risk factor'; nine interviews with front-line HCPs (GPs, Practice Nurses, and Healthcare Assistants); observations of preventative interactions, especially NHS Health Checks (32 hours); and 14 interviews with other 'extralocal' participants who could inform particular aspects of the enquiry (e.g. local NHS Health Check commissioners). Because the IE approach aims to *map social organisation* (rather than, for instance, generate 'themes' or 'theory' from participant samples), a purposive approach was taken to recruiting informants; they were carefully selected in relation to their familiarity with the work processes and texts under investigation. Congruent with this goal, the study also incorporated extensive collection and analysis of documents (e.g. policy, economic analyses, clinical guidelines).

During data collection, Part 1 of the Health Check was easily observed. Part 2 (the focus of this analysis) was more complex because the processes were embedded into a variety of routine clinic work (most often general appointments or telephone consultations). To develop an accurate account of the work involved in Part 2, we therefore relied primarily on interview data. Reliance on interviews as the main (or only) form of data is often necessary in IE analyses where access for ethnographic observation is difficult, but is undoubtedly a limitation. However, using IE's distinctive approach to interviewing (DeVault and McCoy, 2001), we focused on the sequences of action involved in the Part 2 consultation, seeking to avoid the collection of 'professional accounts' which would be far-removed from observable practice. Guided by Campbell and Gregor's (2002: 77) advice that 'the test of whether you are getting a professional account as opposed to an account of what actually happened is if you, the listener, cannot see every step without having to imagine pieces', informants were asked to walk through what they did and said in consultations in order to discuss risk and statins with their patients. Notably, these accounts of their *practices* closely reflected patient accounts of what happened, and observations of other preventative consultations.

From in-depth conversations with patients who described how their experiences unfolded, and from observations of preventative care in practice, we learned about specific troubles. Although diverse and individually unique, these troubles highlighted gaps between what patients (and HCPs) knew from an *experiential* perspective and what they knew from a *ruling* perspective–and established our analytic purpose. These tensions guided us to 'direct attention to a possible set of questions that [were] yet to be posed, [and] puzzles that [were] not yet formulated as such but [were] 'latent' in the actualities of [people's] experienced worlds' (Smith 1987: 89)–a process known in IE as 'formulating the problematic'. The research standpoint was aligned with patients. This standpoint location within the social organisation of CVD prevention provided 'a guiding perspective'–starting with the 'issues, concerns or problems that

[were] real for people and that [were] situated in their relationships to an institutional order' (Smith 2005: 32).

Formulating the problematic

The study problematic brought together multiple disjunctures identified–gaps between what patients (and HCPs) knew from an experiential perspective and what they knew from a ruling perspective. For the purpose of this article, we offer an example of such a disjuncture (selected for its relevance to decision-making about managing risk with statins). We present this disjuncture using two data excerpts which we employ as orientation for the more detailed empirical analysis to follow. The first is taken directly from fieldnotes of an observation and subsequent interview with a patient, 'Sarah', who had accepted an offer of statins. The second is from an interview with a GP, 'Dr Abel', who highlights that statins are clinically indicated following the calculation of a high risk score.

Sarah

I met Sarah [patient] when observing her 'diabetic review'. Sarah had been prescribed a statin following a diagnosis of Type 2 Diabetes Mellitus (the diagnosis increases an individual's calculated CVD risk)–she understood that the statin was one element of the recommended treatment. However, after a while, she became so depressed with her declining wellbeing, which included side-effects from Metformin (a diabetes medication), that she abandoned the statin when friends suggested that it too could also be contributing to her symptoms. During her diabetic review, the practice nurse proceeded through the review template, including double-checking that Sarah was taking the statin. Sarah quietly pointed out that she had stopped doing so, but seemed to avoid a discussion about her reasons for her unilateral action. Afterwards, Sarah told me that she had been reluctant to raise the issue because she thought that the nurse would be unlikely to support her course of action; Sarah understood that the clinical relationship on which she relied could suffer if she contravened advice. She emphasised that she had not taken the decision lightly but that "it's the quality of life that counts". She was keen to find ways of managing her diet and exercise to support this aim.

This short account of Sarah's experience highlights how one patient was concerned about taking statins (in this case, *after* taking them for a while, rather than when *offered* following a high risk score). She knew that they were the recommended treatment, but she also knew that they might be contributing to symptoms she found difficult to bear. She hesitated to discuss her concerns with the nurse for fear of undermining the relationship; the nurse (Lydia), on whose interview we draw later, also appeared to have little interest in pursuing a conversation. Sarah's uncertainties about the value of statins and the symptoms she was experiencing remained undiscussed within her clinical care. This disjuncture in Sarah's account orientates our analysis here.

The second excerpt is chosen because it shows how HCPs know to discuss statins with a patient, and how this is textually organised around the categorisation of a patient as 'high risk'. It is an additional 'view from the ground' into the problematic we are explicating.

Dr Abel

If the risk is high then we would need to contact [the patient] to discuss whether they are willing to be on a statin.

Dr Abel knows that 'if the risk is high' (i.e. risk-scoring technology calculates that the patient has a 10% or greater chance of a heart attack or stroke over the following 10 years (NICE 2014a)) she should offer statins. Her response to the risk score is similar to any other test result such as a high blood pressure reading. She treats the risk technology as a tool to classify disease (see Jutel 2011), for which the recommended treatment is a statin. Her synopsis of what she should do (she needs to check whether the patient is *'willing'*) is in line with evidence-based recommendations in authoritative guidance (CG181). From a fuller analysis of Dr Abel's account, it is clear that she understands herself to be 'following the guideline' and that her goal therefore is not only to *offer* statins but, if possible, to ensure that the patient *takes up* this offer. She knows that a statin is the evidence-based course of action, which is likely to benefit her patient (see 'institutional structures for CVD risk management' above).

The two excerpts above illustrate a disjuncture between patients' individual knowledge (and uncertainties) about how statin medications can be incorporated into their health improvement work, and what we are describing as institutional or 'ideological' knowledge. According to Smith (1987: 55), ideology consists of 'ideas and social forms of consciousness [which] originate outside experience, coming from an external source and becoming a forced set of categories into which we must stuff the awkward and resistant actualities of our worlds'. Such conceptual forms of knowledge (and the *practices* which are inextricably linked to them) 'deny expression to the actual experience people have in the working relations of their everyday world' (ibid.). When people act according to an institutional knowledge which is at odds with their (or others') local, embodied experience, this can be described as 'ideological practice'. We highlight 'ideological' knowledge and practices as we progress this analysis.

Disjunctures such as that highlighted above raised questions that contributed to the formulation of the problematic (the tensions to be described and explicated). Questions included: 'How is it that patients struggle to bring uncertainties about preventative technologies (e.g. statin medications) to the attention of HCPs, and have these attended to?' 'What is the social organisation of guidelines' directions for 'shared decision-making'?' 'How do these enter into HCPs' work?' 'And in whose interests?' As we explicate this problematic, we explore a 'particular corner' within the institutional complex of CVD prevention, to make visible the 'points of connection with other sites and courses of action' (DeVault and McCoy 2006: 17). We explore how HCPs activate institutional knowledge of CVD risk and evidence-based risk management in Health Check consultations, and how this intersects with the work of patients who feel unsure about raising their uncertainties about preventative medications with HCPs.

Activities of evidence-based risk management: guidelines, uncertainty and informed decisions

As we have outlined, the risk score is an important text within the institutional structures of CVD prevention and particularly in the Health Check, which is structured around its calculation. Pertinent to this analysis is how the texts embedded in the Health Check are organised to abstract each patient's 'lifestyle', biological and socioeconomic particularities into a category of 'overall risk'. The data collected, as directed by an electronic template, are subject to a behind-the-scenes algorithmic calculation, based on aggregated data from epidemiological studies. We note therefore that practices of delivering the Health Check are designed to separate individuals from the unique circumstances of their lives; that is, they are 'ideological' in the sense used in IE. This ideological knowledge, on which the risk score and the recommendation to offer statin treatment are based, provides a position of 'certainty' from which HCPs work to

introduce discussions of CVD risk and preventative medications. In the following extract, Dr Sully (a GP) exemplifies such certainty:

> The evidence behind what we do is absolutely top drawer [. . .] no one would argue [. . .] so you know, it's about having a conversation with a patient and saying 'these are the guidelines, we know this works, these are the benefits and these are the risks, you decide'.

Dr Sully understands that it is his responsibility to communicate to his patients that preventative medications 'work'–in other words that they will prevent heart attacks and strokes. Despite the complexity of the evidence base, and its ambiguous relevance for his individual patient, Dr Sully confidently brings abstracted knowledge about population health to the encounter. The knowledge he activates has become binary in its guideline form: an individual is 'at risk', or 'not at risk'. Similarly, interventions either 'work' (and are recommended in guidelines), or do not 'work' (and are omitted from guidelines). In Smith's (2005: 18) terms, both Dr Sully's '*consciousness*' and his *practices* (the way in which he communicates to his patients) are shaped through his reading of guideline texts. He trusts the institutional processes of guideline development to provide him with clear-cut knowledge of risk and of 'what works', and he draws on EBM's established narrative to emphasise the certainty of this knowledge when he speaks with his patient. For him, this is the requisite 'knowledge for taking action' (Rankin and Campbell 2006: 7)–the textual certainty which allows him to move quickly to statin prescription. The *uncertainties*–what benefit might be gained for a particular patient–recede from his view.

The scientific knowledge of risk and preventative treatments jars with the uncertainties of front-line clinical encounters–and in the work of both patients and HCPs. This disjuncture is in Sarah's quiet, almost surreptitious act of terminating her use of statins, and in Dr Abel's description of her work to cultivate a patient's willingness to take them. Risk scores, as noted above, bring a person's whole life into view as a single measure of CVD risk. How then can HCPs make this standardised and remotely calculated knowledge meaningful to an individual patient? CG181 responds to these difficulties by providing extensive guidance on how risk should be 'communicated' to patients–a plethora of directions that augment the recommendation to prescribe statins for all patients who exceed the 10% risk threshold. These include advice to allow 'adequate time' and to use easy-to-understand language and visual tools that provide a simple way to illustrate and explain risk statistics. The guideline emphasises that:

> the decision whether to start statin therapy should be made after an informed discussion between the clinician and the person about the risks and benefits of statin treatment, taking into account additional factors such as potential benefits from lifestyle modifications, informed patient preference, comorbidities, polypharmacy, general frailty and life expectancy (p.17).

However, despite these explicit directions and the tools provided, the HCPs we interviewed found the epidemiological probabilities difficult to explain to patients, and consequently steered away from such explanations of risk. When they attempted to bring this form of knowledge to their patients, tensions arose; discussions did not unfold in the straightforward way that the directions and tools are designed to support:

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

> I don't think [HCPs] talk about risk [. . .] Most patients are innumerate. If you say to some-body, 'You're at 30% ten-year risk', they don't understand. Scarily, substantial numbers of doctors don't understand. (Dr Smart, GP)

Although presented here as a problem of statistical competence (of both patients and HCPs), our data show that the tensions arising in front-line practice are more troubling than issues of numeracy. The abstract, scientific knowledge of risk scoring *creates new work* for HCPs tasked with bringing it into an individual consultation. Lydia describes the work she under-takes to make a risk score and statin treatment meaningful to her patients:

> I have to explain that [the risk score's] looking at your blood pressure, it's looking at your weight, it's looking at your sex, it's looking at where you live, it's looking at your family history, it's looking at your cholesterol. So [cholesterol's] just one marker. (Lydia)

Lydia provides an overview of the types of data included, and how demographic factors (such as sex, neighbourhood and family history) and clinical markers (blood pressure and cholesterol levels) produce an all-encompassing and authoritative score. She notes that helping patients understand risk scoring is made particularly difficult by the recommendation to treat a high risk score with statins *even when the patient does not have an elevated serum cholesterol.* Although based on trial evidence that cholesterol-lowering is beneficial whatever the baseline, this knowledge is counter-intuitive for patients. Similarly, Dr Abel describes how patients also raised other concerns about taking statins, demonstrating disjunctures between their own knowledge and that of epidemiology and evidence-based risk management:

> Some patients are very keen to have [statins] because they've heard that it helps to reduce the risk of heart events and stroke [laughs]. Others have heard some of the more negative publicity about statins, or they've had a relative who's been on them and had bad leg-ache, for example, and don't want them. Some people want to try diet and exercise first. (Dr Abel)

The HCPs reported that patients regularly raised such queries, preferring to avoid statins if possi-ble (as Will and Weiner (2015) have similarly shown), and bringing knowledge from debates aired in fields beyond medicine (e.g. news media) (see Stevenson *et al.* 2003), in support of this alternative knowledge rooted in the 'actualities of [their] worlds' (Smith 1987: 55). For instance, patients asked about side-effects (which were anecdotally reported to be much more prevalent and severe than suggested by guidelines), or whether they could address their high risk score by making dietary or exercise changes alone (recognising that important aspects of their health such as obesity would not be solved by taking a statin). When they asked such questions, patients were not primarily wishing to engage in complex discussions of the research evidence, but were interested in its *application* to the particularities of their own lives. With regard to the science itself, they appeared more comfortable trusting their HCPs' judgement about whether statins would be a good idea *in their situation, within the context of their own everyday life and prefer-ences*. One patient encapsulated his uncertainty with a question (which he hoped his GP would answer): 'Does it *make sense* [for me] to take a statin?' HCPs like Dr Abel and Dr Sully, how-ever, resolutely drew on a narrative of EBM to answer this sort of question with certainty. Sta-tins, within the scientific form of knowledge espoused by EBM, 'make sense' for all patients with a high risk score: they 'work'. Rather than working with the patient to explore whether a statin would fit with their individual circumstances, HCPs described how they actively promoted compliance as the foundation of their responses to patients. They framed the reluctance that underpinned patients' queries as a 'barrier' to the expected course of action:

You have the barriers to start breaking down. So it's 'What do you know about statins?' 'What have you heard about statins?' 'How would you feel about taking them?' And then you explain to them what the side-effects are. If they have the side-effects then let me know because I will stop the tablets. It's up to them, they don't <u>have</u> to take them if they don't want to. It's going to reduce their risk, but I can't say for definite that it means that they won't have any problems. It has to be their choice. (Lydia, Practice Nurse)

Lydia, like Drs Abel and Sully, persuades her patients to accept preventative medication through a process of identifying, and then breaking down, their 'barriers'–correcting what appear to her to be their misconceptions. It is at this point of potential non-compliance that she employs techniques represented in CG181 and other guideline texts as strategies to 'involve' the patient. Delivered as simple one-liners (e.g. 'What have you heard?'), Lydia's questions help her to meet multiple institutional requirements; she understands her pithy questioning to both 'involve' the patient, and also to keep the patient on course for a medication prescription. She is focused on medication adherence even as she recognises that the patient may have 'problems', and that trying to overtly pressurise patients is likely to be counterproductive.

Although our data suggest that HCPs make efforts to encourage patients to modify their lifestyle behaviours (usually with short questions and prompts during Part 1 of Health Check process), HCPs undertaking Part 2 (the conversation about risk and statin medications that we are explicating here) are careful to ensure that patients are not derailed from a medication-oriented course of action. Dr Abel reported for instance that, while keen to highlight particular lifestyle risks and (rhetorically) encourage patients to make changes, she is also careful to ensure that they do not put their hopes in lifestyle change as a potential *alternative* to medications–that they are not distracted by attempting to 'try diet and exercise first' (earlier excerpt). Whilst she is attentive to CG181's directions that she should 'discuss the benefits of lifestyle modification and optimise the management of all other modifiable CVD risk factors' before offering a statin, she simultaneously undertakes to 'warn people that [lifestyle change] doesn't always work'–putting them off a course of action which might seek to bypass medications. After a patient is classified as being at 'high risk', lifestyle change is no longer the primary focus of her prevention work. Her *own account* indicates that such discussions are shaped by a knowledge framework which prioritises the prescription of preventative medications above such lifestyle action.

Absorbing professionals into the ruling relations of CVD prevention

As we have shown, the discursive practices of risk management embedded within the institutional structures of EBM strongly organise HCPs' front-line work–to the extent that their work to manage risk using *medications* dominates over other work to meaningfully 'involve' the patient and to support behavioural change–even though this is also promoted within CG181. To grasp how this organisation works, we scrutinise HCPs' practices to apprehend the tensions generated within the prominent discursive terrain of 'patient-centredness' and 'shared decision-making'. The HCPs on whose accounts we have drawn all emphasised that patients are not compelled to take medications. Dr Sully, when gently challenged that a patient might feel coerced into starting medications, strongly disagreed: 'the idea to suggest that we're there to push medication is stupid, and I don't accept that at all'. However, we note that, simply by providing an option to reject the guideline recommendation (see earlier excerpt), he could frame his practice as 'sharing decisions' with patients; he had *shared* the authoritative and

standardised information on benefits and risks and it was now down to the patient to *'decide'*. However, rather than a collaborative process in which patient and HCP work together to identify the best course of action for the individual patient, the 'discussion' has become a transaction, and (even from these HCPs' *own accounts*) it appears that such interactions offer little to help patients manage the uncertainties and problems thrown up by the risk score.

As HCPs drew their patients into actively 'choosing' the institutionally sanctioned course of action (seemingly overruling patients' queries and uncertainties) they simultaneously used language such as 'patient-led', 'communication', 'involvement' and 'shared-decisions', thereby constructing a belief that they were enacting these patient-focused values. However, the language of 'patient-centredness' and 'shared decision-making' used by HCPs conceals the ruling relations of CVD prevention; such 'involvement' work brought with it the institutional agenda of compliance with standardised forms of risk reduction whereby 'involving' patients is supposed to result in 'better decisions' through which patients are understood to be "more likely to adhere to their chosen treatment plan" (NICE 2014c: 82). Smith (2005: 155) describes this shaping of people's consciousness in line with ruling relations as 'ideological (or institutional) capture', in which people (research participants, researchers or others) draw on institutional discourse to displace their own understanding of what is happening. Ideological capture works to blind people to what is going on. Although they *may* experience some disjuncture (Campbell and Gregor, 2002), they may nonetheless *gloss over* such moments, treating tensions as an ordinary, acceptable feature of doing good work. HCPs' 'captured' understanding of patient-centeredness clashes with patients' difficulties with discussing their uncertainties about their health needs and the relevance of statins. Their work overlooks patients' anxieties and struggles with improving their health, especially for those patients with unhealthy 'lifestyles', towards whom CVD prevention interventions are particularly aimed.

The complex of social relations organising preventative decisions: monitoring CVD prevention through GBD metrics

So far, we have focused on the risk score and an institutionally constructed rhetoric of shared decision-making as components of the textual organisation which shapes preventative care. We have highlighted some of the tensions between authorised knowledge of risk management and patients' own understanding of what they need to improve their health, and particularly their desire for support with addressing their uncertainties about statin medications. We have drawn attention to the 'everyday' practices of HCPs that reinforced the authority of ideological knowledge in preventative consultations–practices that are detrimental to their relationships with patients. We have noted that HCPs may become so focused on evidence-based risk management with medications that they forfeit attention to patients' experiences of improving their health and sidestep their concerns and uncertainty about what to do–even whilst understanding themselves to be 'involving' patients. We have explicated these tensions as a feature of how ruling relations are activated–turning a patient's body into epidemiological information and rendering it as a 'case' (as we elaborate below) that can be turned into quality 'outcome' metrics to demonstrate the success of CVD prevention.

In this final section, we shift our gaze towards the broad textual relations of Health Checks, risk scores and CVD prevention guidelines. We follow threads of analysis into the governance of health care in England and beyond–into the institutional structures of the GBD discourse. IE's focus on institutional ruling relations shifts the focus of analysis from a critique of individual HCPs (who may be accused of slavishly following guidelines, for instance), to examine instead how HCPs' attentiveness to *particular recommendations* is coordinated within an

'intertextual hierarchy' (Smith 2006: 79), dominated by what Adams (2016: 6) describes as 'technologies of counting'. At their highest level of abstraction, these technologies supply apparently neutral knowledge about the 'burden of disease' and what should be done to reduce that burden.

In England, Clinical Commissioning Groups (CCGs) are part of the complex organisational structures which govern healthcare provision. An informant interview with Luis (a commissioner) provided a clue into how the Health Check generates metrics of risk condition prevalence (including overall risk), evidence-based treatment (e.g. statins) and CVD outcomes that organise HCPs' work with their patients. He explained:

> From a CCG monitoring point of view, the main output [from the Health Check programme] is the **number of Health Checks delivered**, but it also feeds into things like concerns about **prevalence of long-term conditions** [as measured through GP electronic systems]. So we would be interested in the number of new patients diagnosed with diabetes, for example, or the number of new hypertensives identified and started on evidence-based treatment. [. . .] That is part of a structured, iterative approach in primary care to **ascertain new cases, managing them early**, and we know from a CCG point of view, that there is a relationship between managing hypertension well, finding new hypertensives [. . .], and a **reduction in terms of early mortality and morbidity** from things like stroke, MI and so forth. (emphasis added)

Here, although Luis does not talk explicitly about the 'burden of disease', he understands that measures of the prevalence and treatment of risk conditions are important proxies for how effectively local managers are tackling the burden of disease (in terms of both *lives* and *costs* saved)–measures which would be highly visible to national CVD prevention policymakers (e.g. Public Health England 2015). Our data show that local policymakers' work was tightly oriented to the GBD 'sphere of activity' highlighted in our introduction–coordinated work and talk focused on statistical measures of disease burden (see, for example, Department of Health 2013; Newton 2017), which were also translated into projected cost savings (Kearney and Freeman 2016). Local policymakers in turn drew front-line HCPs into this focused activity to address their local burden of disease–monitoring proxy measures such as risk condition prevalence (health centres with a high recorded disease prevalence are understood to be doing well at identifying 'new cases') and the pharmaceutical treatment of those newly identified risk conditions. Through benchmarking and variation modelling, general practices across regions were compared, and the lowest performers targeted for improvement interventions.

Within the constraints of this article we cannot explicate in detail *how* such performance measures enter into HCPs' everyday work or how, *in practice*, HCPs' work to 'try, adjust, and try again' in the face of multiple uncertainties (Mol 2008: 22)–to 'care'–is sometimes 'organised-out' of preventative interactions. However, GP informants in this study described how they were acutely conscious of the way in which select CVD performance measures are monitored and made publicly visible. It was these measures that coordinated attention within general practice to making 'adjustments' to data in preparation for governance scrutiny. They explained that they were not only *financially incentivised* to identify and treat CVD risk conditions through the Quality and Outcomes Framework (Cupit 2018; NHS Employers *et al.* 2015, Appendix 4), but, for some, more importantly, their *reputations* were at stake as local policymakers used the data to judge GPs' performance. This explication of how patients' frustrations and uncertainties are organised shows how managers and front-line HCPs are increasingly drawn into tightly focused work in which a *limited set of measures* are understood to provide

knowledge of what happens locally; that representation is concurrently used to drive action directed specifically towards improving *those measures*.

Institutional ethnographic researchers have described the circular forms of action such as those described above as 'accountability circuits' (Griffith and Smith 2014: 10). The circular accountability practices of CVD prevention are produced by multiple, interrelated textual processes which, we argue, are orientated towards quantifiably reducing statistical measures of the 'burden of disease'. They include economic modelling processes which shape the way preventative care is fragmented across different HCP roles. Such accountability practices have consequences which, although apparently unintended, are *socially organised* to happen as they do. The scrutiny imposed on health centres' electronic health records organises HCPs to systematically overlook the very many uncertainties of patients' individual health needs, and what might be gleaned during HCPs' front-line interactions (their 'clinical judgement'). It directs them instead to promote adherence to pharmaceutical interventions in favour of ongoing adaptive support for improving health more broadly. As Dr Smart, for instance, admitted, 'the temptation is there to push people to do stuff that you wouldn't feel you need to do'. This may have significant detrimental consequences for therapeutic relationships between HCPs and patients, and limit the opportunities for genuine support for patients' lifestyle change.

Discussion

Our analysis started with the work (and the tensions) as experienced by patients. We used the empirical tools of IE to explicate how CVD knowledge is organised–how it arises as a ruling relation inside front-line practices (in which HCPs introduce concepts of CVD risk and risk management), and subordinates genuine shared decision-making. HCPs activate a narrative of evidence-based risk reduction as a 'practice of knowledge' (Mykhalovskiy and Weir 2004), which evokes (ideological) certainty in their preventative encounters with patients. Organised to selectively draw on this narrative, HCPs preserve the 'dualism between disease and non-disease' which Jutel and Nettleton (2011) have previously claimed was 'collapsing in the face of new categorisations of potential disease and risk factors'. They overrule uncertainty in the clinical encounter and instead outsource the work involved in managing the uncertainties about risk diagnoses, pharmaceutical treatments and other preventative options (such as lifestyle change) to patients–to be managed within whatever private networks and resources are available to them, away from the clinical encounter.

Our analysis highlights how HCPs' presentation of *particular forms* of preventative action (and their beliefs that these actions are incontrovertibly beneficial) creates difficulties for patients, adding to the 'work of patienthood' (May *et al.* 2014). Our analysis therefore also provides an explication compatible with the analyses of others who have studied patients' understanding of risk or uncertainty. For instance, Polak (2016) found that many patients understood statins to be 'needed' to treat a current condition (not a modelling of risk), and Saukko *et al.* (2012) highlighted the role of risk assessment technologies in patients' approaches to medications and alternative courses of action. We have explicated how patients' practices of knowledge (e.g. how they think about the present and the future, how they make decisions about medications, or understand the relevance of lifestyle change) are *powerfully shaped* through their socially organised interactions with HCPs–whose ruling knowledge about risk and risk management subordinates other locally situated knowledge and individual dilemmas about what to do. We bring attention to how risk assessment technologies enable the *conceptual* textualisation of a patient's individual health needs as 'risk'–a concept that is then used in aggregate, to demonstrate and drive improvements in highly selective 'burden of

disease' measures. This is how concepts associated with GBD and evidence-based risk management land into clinical encounters as (ideologically generated) tensions and contradictions–coordinating individual HCPs' knowledge and capacity for action. Throughout this article, our argument is not to show that risk scores, evidence-based treatments or performance measures related to demonstrating reductions in the burden of CVD are 'bad', but to show how they powerfully coordinate people's activities, their energies and their consciousness (from policy-making to the frontline) in ways that, paradoxically, within a rhetoric of shared decision-making and concern to support behavioural change, preclude HCPs' capacity to respond to the subjectivities and uncertainties of individual patients–to 'care'. Although many authors have challenged the role and impact of performance measures, this study is unusual in that it begins a process of mapping and tracking how the 'conceptual practices of power' (Smith 1990) enter front-line clinical practice–how they are produced and reproduced as textual (empirical and material) organisers that obscure a robust analysis about what is actually happening in patients' encounters with HCPs, and how these encounters undermine patients' attempts to improve their health within the everyday contexts of their individual lives.

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Acknowledgements

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