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# **Rethinking decision-making in the context of preventive medication: how taking statins becomes “the right thing to do”**

**Louisa Polak and Judith Green**

## **Abstract**

To understand decision-making in the context of longterm preventive medication, we explore the way “deciding” articulates with household medication practices and other everyday routines. Taking statins as a case study, we use qualitative data from interviews with 34 participants in the UK who had all been offered statins; 19 were currently taking them. Although all participants reference similar information about statins, the way they assemble and use their knowledge varies: there is a marked asymmetry between participants taking statins and those not taking them. Deliberation is a prominent feature of accounts of deciding not to take statins, but seldom visible within accounts of those taking them. Statin-takers emphasise that they have “no choice” about taking them, while non-takers stress the need to “think about it”; statin-takers’ accounts prioritise biomedical tests over experiential knowledge, whereas non-takers sometimes prioritise experiential knowledge. All participants reference similar theoretical and experiential knowledge about side-effects, but whereas non-takers often use this knowledge to explain their decision to decline statins, those taking statins downplay both their own experiences and the likelihood that these are due to statins. To account for these asymmetries, we propose a model of decision-making in which deciding upon a course of action entails constructing a narrative presentation of medication use that frames it as “*the right thing to do*”. This model helps us examine the two-way interactions between decision-making and the material practices through which regular medication gets taken, interactions often elided from accounts both of decision-making and of medication practice. In the context of longterm medication, the boundaries between “deciding” and

“doing” are blurred; decision-making is situated within a web of collaborative, discursively-informed practices.

**Key words**

UK; decision-making; medication practices; knowledge construction; qualitative; statins

## **Introduction**

The increasing use of longterm preventive medication is advocated by many recent policy documents and guidelines. Statins - taken to reduce the risk of future cardiovascular disease - are one such example, with UK guidelines now recommending that they should be offered to people whose risk of cardiovascular disease within 10 years is 10% or above [NICE 2014]. This and much other policy guidance on preventive medication in the UK advocates shared decision-making between clinicians and patients [NICE 2019]. Shared decision-making, then, has been widely accepted as a goal of clinical practice, if less widely adopted by practitioners [Stevenson et al 2000]. However, including shared decision-making as a goal indicates the widespread acknowledgement that decision-making is an essential element of the process of “following guidelines”; ethical and political norms direct that medical decisions should be taken by, or at least with, patients. There is, perhaps, a particularly strong case to be made for “patient participation” in decisions about longterm interventions such as using preventive medication [Montori et al 2006]. Our research looks at the way people who have been offered such medication account for their decisions about whether or not to take it.

To examine decision-making in the context of preventive medication, we engage with two largely separate bodies of research: one is focused on medical decision-making, the other on illness work and medication practices. Much existing research foregrounds the phenomenon that many people do not take their prescribed medication, particularly preventive medication like statins (Jackevius et al [2002], Benner et al [2002]). In order to understand this phenomenon, and to construct an account of the way people do take statins, we explore the way deciding about medication articulates with taking it regularly at home.

While medication practices are widely framed as socially and materially embedded in the routines of everyday life, decision-making is still largely considered as a predominantly cognitive process, centred on deliberation. Writing about what constitutes “a good decision”, for instance, Elwyn and Miron-Schatz [2010] describe its key process as “deliberation... [followed by] choosing an option”. This process of thoughtful choice is explicated in a number of empirical sociological studies reviewed by Pound et al [2005], who synthesise qualitative evidence that people “weigh up the benefits of taking [medication] against the costs of doing so”. Benson and Britten [2002] report that participants in a study of people taking blood pressure pills “balance reservations against reasons for taking [their medication]”; and Crinson et al [2007] discuss the ‘active process’ of decision making as typically involving “assessment by the patient of the expected benefits of this medication ... balanced against potential and actual side-effects”. In such empirically grounded accounts, then, weighing and balancing are identified as prominent features of decision-making. This prominence is also visible in more normative work [Elwyn et al 2014] by a group that includes many leading authors in the field of shared decision-making: comparing “alternative potential courses of action” is a central component of their proposed model of “collaborative deliberation”. Their model portrays decision-making as distributed over several clinical encounters, drawing on accounts [Charles and Gafni 1997; Montori et al 2006; Rapley 2008] that highlight distribution not only over time but also over multiple interactions with a range of other people and technologies, in a range of different places.

Framing decision-making as distributed in these multiple dimensions broadens 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, the concept of distributed decision-making remains limited by an overly-cognitive model of what is going on. Contrasting distributed decision-

making with conventional models, Rapley [2008] describes each episode of deciding as “another-decision-in-a-series”; his heuristic, “distributed cognitions”, suggests that the primary role of all the multiple interactions described is to collect information that is used in “making up one’s mind”. Such cognitive framings imply a separation between deciding about pill-taking and enacting pill-taking, with “a decision” preceding action in a linear sequence. This sequence is also clearly indicated in Elwyn et al’s [2014] exposition of the collaborative process through which a patient works with a clinician to reach a decision: “Eventually, decisions are enacted, behaviors initiated”. The authors explicitly situate this enaction off stage rather than incorporating it within their model.

This separation between making and acting upon a decision also underpins research that asks why people do not take prescribed medication. Framed in the biomedical literature as “non-adherence”, this is identified as “a common and costly problem” [Marcum 2013], and much research attempts to explain and overcome the “barriers” to adherence. These explanations generally centre on the way patients understand the medication’s purpose. Lau and Kriegbaum (2018), for example, examine patients’ perceptions of “the uncertainties related to statins” in their study of non-adherence. The authors describe the distributed and socially-situated ways in which patients collect information and build knowledge, challenging the assumption that the way to improve statin adherence is to get clinicians to explain statins’ benefits better. Lau and Kriegbaum consider “the active action of statin discontinuation”. This echoes a body of qualitative research that has reframed non-adherence, asking what people are achieving in “accepting”, as well as “rejecting” or “resisting” medication [Dowell and Hudson, 1997; Pound et al, 2005]. However, the focus on deciding as distinct from doing remains; Pound et al, for instance, mention material medication practices only as something “active accepters” may decide to modify so as “to make the regimen more acceptable”.

A separation between deciding and doing is also implicit in the growing literature that explores the way people take regular medication. For example, in Dew et al's [2014] account of household medication practices, decisions about taking medication are visible only via reports of what was said and done in encounters with clinicians, at another time and place. Others portray medication-taking as just one element of the shared work of living with a longterm illness or condition [Corbin and Strauss,1985, Pickard and Rogers, 2012, Vassilev et al,2011, Cheraghi-Sochi et al,2015]. Langstrup [2013] and Weiner and Will (2018) build on these approaches, using the concept of care infrastructures as a heuristic that foregrounds the way people, objects and spaces interact to co-constitute practices of care. A similar emphasis on emplacement informs Hodgetts et al's [2011] research on everyday medication use. In this body of research, home is presented as the place where most of the work gets done, while the cognitive work of decision-making is implicitly situated offstage in clinical encounters and settings.

Thus accounts of care practices and shared work mirror descriptions of distributed decision-making: both groups of accounts emphasise interactions with multiple people and technologies and an expanded spatialisation in place and time, while each group leaves the other out of the picture. Our research builds on both these bodies of research, and examines the articulations between them. Drawing on findings about the way people account for their medication practices, we construct a model of decision-making that helps understand why some people who are advised to take regular preventive medication end up taking it while others do not.

## **Methods**

Our data are from a qualitative interview study of 34 people in one region of the UK aged between 53 and 87, all of whom had been offered statins. Potential participants were told we

were interested to talk to anyone who had been offered statins, to find out how they made up their minds whether or not to take them. They were recruited in non-clinical settings, using invitations to community groups and snowballing from initial participants in four rounds to enable theoretical sampling on the basis of ongoing analysis. Community groups were selected to identify a range of participants in terms of socio-economic status, including recreational associations, an exercise class and a community lunch club. When a participant's partner was present, we obtained consent from both individuals before the interview; where the partner turned out to have been offered statins themselves, they were recruited as a participant in their own right.

At the time of interview, nineteen people said they were taking statins. Sixteen participants said they had suffered a heart problem requiring urgent hospital admission; several expressed uncertainty about the precise diagnosis but all mentioned heart attack, angina or blocked arteries. In the findings presented here, everyone in this group is referred to as having had a heart attack, to distinguish them from participants who had been offered statins without ever having suffered a sudden alarming episode of this kind. The two groups might conventionally be understood as having been offered statins for secondary and primary prevention, respectively. However, as the study was entirely community based, we did not seek to check information about medication or diagnosis with participants' doctors, and we did not make any a priori assumptions about differences between the two groups.

Interviews (all conducted by Polak) covered 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. Twenty two were interviewed with their partner and twelve individually. Almost all interviews took place in participants' homes, providing an opportunity to observe some material practices and



technologies related to pill-taking. In the couple interviews, some of the shared work of knowledge construction that underpins decision-making, and the co-construction of accounts of participants' decisions and actions, was also enacted [Polak and Green, 2015]. Ethical approval was obtained from The London School of Hygiene and Tropical Medicine before data collection began. All names in this paper are pseudonyms, and identifying material has been removed.

Analysis of participants' accounts used elements of the constant comparative method; of particular value were comparisons that emerged between people who were taking statins and people who were not, and between people who had had a heart attack and people who had not. These comparisons informed theoretical sampling; for example, early cycles of interviewing and analysis suggested a need to recruit participants who had had a heart attack but who were not taking statins. Using the symmetries and asymmetries between data from these different groups, we constructed an 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 daily pill-taking, highlighting the way a decision both informs everyday routines and is underpinned by them. We first identify some limitations of a cognitive model of decision making, in which reasons to take medication are balanced against reasons not to. Next, to address these limitations, we consider three questions: How do people construct knowledge? How is knowledge used in accounting for decisions? And how do decisions about regular medication articulate with everyday medication practices?

## **Decision-making models centred on deliberative choosing: a poor fit with these data**

Deliberation is a key constituent of decision-making in the literature, but in our data there is a striking asymmetry between those taking and those not taking statins (henceforward “takers” and “non-takers”): deliberation is seldom visible in data from interviews with statin-takers, but frequently visible in non-takers’ accounts.

Julie stopped taking statins recently. She is 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.*

This account appears to describe a classic deliberative process. Julie indicates some of the work of knowledge construction that supports deliberation; she acquires and evaluates information in a series of interactions distributed over time, drawing on a variety of resources including her husband, and newspaper reports. In this respect, what she 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. Yet Julie's account is, in many ways, a poor fit with the standard decision-making model. She is not weighing up the risks of breast cancer against the risks of a stroke, but 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: when asked how they came to decide against statins when offered them, several non-takers say *“you have to think carefully about it”*, and some, like Julie, offer detailed accounts of this thinking. In contrast, data from the interviews with statin-takers gives almost no indication of deliberation. Instead, when asked how they came to be taking statins they reply by explaining why they *need* them. They offer two kinds of reason for this need: a problem that needs treating, such as cholesterol or heart problems, or a doctor’s directive advice, or sometimes both together. In the data as a whole, “choosing” to take statins is only explicitly referenced negatively, where a taker explains that because the medication is necessary, they have *no* choice about it. Nobody says they “chose” to take statins.

For instance David, Julie’s husband, has been a statin-taker since his heart attack. 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 regular medication to prevent asthma attacks: *“you've had asthma, that doesn't even really need to be talked about”*.

In these data, indications that a medication practice does “*need to be talked about*” are found almost solely in non-takers’ accounts. Despite this difference between takers and non-takers, there is a similarity regarding the work that their accounts do within the interview: both takers and non-takers produce a story that they are comfortable presenting, to themselves as well as to others. The construction of this presentable story is cast as “deciding” in our new model of decision-making. To explicate this model, we next consider the way knowledge gets constructed and the way it is used, two key constituents of the deciding process.

### **Constructing a story about “*the right thing to do*”: gathering and assessing information**

The first step towards deciding what to do involves gathering information in order to construct knowledge. Participants describe using interactions with multiple people and things to acquire information about statins. 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 the interviews themselves, as participants pick up a newspaper to show a recent headline, or look through a pile of papers on the sideboard to find an information sheet they got from the hospital, or point to their copy of a Diabetes UK magazine on the coffee table.

A lot of information about statins is surfaced in these data, information evidently held in common by most participants, takers and non-takers alike: 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 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, for instance, they visibly co-construct their shared theoretical knowledge:

*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.*

Peter and Wendy go on to describe a wide range of information-collecting strategies, include reading online and in magazines about heart disease and its treatments, indicating that this is shared not only between the two of them but also with their son who is a paramedic. Several other participants mention children, friends or acquaintances who were involved in the work of information-gathering; for example, Gill and Simon’s daughter “*was the one that had the computer*”.

As well as helping them build theoretical knowledge, interactions with other people also extend participants’ experiential knowledge; many people indicate knowing that a stroke is a terrible thing because, for example, Jim’s father had one and “*it was horrendous to see the poor old boy*”, while Neil talks about the reassuring effect of talking about his own experiences with others who have had heart attacks: “*when I talk to anybody else, they have all got the same*”.

So our findings demonstrate that collecting information about health problems and the role of long term medications is distributed, involving multiple interactions with people and technologies. This general information gets combined with theoretical and experiential information about one's own body. Peter talks about personal, theoretical 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 describes himself as passive, waiting for Dr X to tell him the results, Peter also describes more proactive processes of 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. 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. For instance, our data often indicate a clash between test results and bodily sensations, which could each be presented as potentially undercutting the other's credibility. Where participants negotiate these tensions or clashes, test results often trump sensations, particularly in statin-takers. Amongst those people who

have had heart attacks, several echo Horlick-Jones' [2011] account of a loss of confidence in sensations of wellness or illness, following an alarming and unexpected illness. Peter exemplifies this, in his 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*

He tells a vivid and detailed story about 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 test results can undermine feeling well; they can also undermine feeling ill, as 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.*

Like many statin-takers, then, Keith ranks tests above feelings. In contrast, non-takers' accounts sometimes indicate that test results and related medical advice are trumped by feeling well. Walter exemplifies this, explaining why he stopped taking statins soon after being prescribed them: 'Why dabble with something when you feel everything is ticking along nicely?'

These findings challenge accounts of knowledge construction that centre on assembling a pile of implicitly stable, context-neutral information. Instead they suggest a dynamic, discursively-informed process that can be understood as a collection of sociomaterial practices. This framing is helpful for considering the way knowledge gets used.

### **Using knowledge in making decisions**

In our model, “a decision” means “a story that one is comfortable presenting”. Knowledge is used to support the construction and presentation of this story. The same knowledge may be used to support two different stories, through a ranking process similar to the one used in knowledge construction: just as participants make judgements between competing pieces of information in order to build a coherent body of knowledge, they also make judgements about whether a given body of knowledge is placed at the centre or at the periphery of a story about the right thing to do. This is illustrated by the different ways in which participants use widely-shared knowledge about side effects.

#### ***Same knowledge, different ways of using it: the example of side effects***

Almost every participant talks about statin side effects; most mention muscle pains, referencing both general and personal knowledge, and many refer to the amount of conflicting information available. Yet statin-takers’ talk about side effects differs from the talk of non-takers, not in terms of the information content referenced, but in terms of the role this information is given within accounts of medication decisions.

Several non-takers use side-effect information to explain their decision. For instance, replying to a question about why she stopped taking statins, Debbie 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 worsening arthritis would obviously justify stopping medication. This



justification work is visible particularly clearly in the account offered by Bert, one of the few non-takers who has had a 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*

Bert illustrates that after strong medical advice to take statins, legitimating not taking them requires hard work: in order to present stopping statins as the right thing to do, he describes extreme, intolerable side effects, mentions that he persevered despite these for months, and also reports his doctor's advice.

Taken alone, these examples seem to suggest that side effects make people decide to stop statins. But this simple story rests on the assumption, widely visible in the biomedical literature, that side effects are stable objects about which one can collect robust "facts". Our findings complicate that assumption, because statin-takers, too, mention unpleasant-sounding phenomena and ascribe them to statins. Jim says that "*I get muscle wastage now, I've got all this skin it's all hanging*". He explicitly describes this as being due to his statins, yet he gives no indication that he has balanced it against statins' benefits or considered stopping taking them; 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 concerns exaggerate both the severity of the side effects and the likelihood that they are “*down to*” statins in the first place.

The difference between takers’ and non-takers’ accounts is thus not a difference in the knowledge they reference; what differs is the role of this knowledge in the story they present about what they are doing. In stories told by non-takers, particularly where people have tried statins and then stopped, knowledge about side effects has a central role. In contrast, many statin-takers 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 without saying. This contrast suggests that whether or not someone takes statins is not determined simply by rational use of explicit knowledge. Instead, this theoretical knowledge gets combined with often-tacit practical knowledge and values to constitute a discourse about “*the right thing to do*”. In the next section we explore this combining process by focusing on data from interviews with statin-takers, people for whom (in these data) taking medication is something that “*doesn’t ... need to be talked about*”. The question is, what tacit knowledge and discursive framings have to come together to confer this taken-for-granted status on the rightness of regular pill-taking?

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

The material practices that produce and support daily pill-taking have a key role in establishing its “ordinary” status. This can be seen in descriptions of interactions both outside and inside participants’ homes, and in talk about medications in general as well as about statins in particular.

Henry and his wife Liz are explaining 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*

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 people who remember to *'just'* take their pills. Their account also references 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 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. Like aspirin, statins are presented as reassuringly ordinary by several participants who say they take them. Geoff, for instance, is in his 50's and often travels for work with a group of colleagues, many of whom he assumed would also be taking statins:

*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.*

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.*

Kathy's account suggests that it is common knowledge that grapefruit can't be eaten if you are taking statins, and that it is commonplace for people her age to take them. The communal experience of 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*". We suggest that, in the context of longterm medication, this "*idea*" constitutes a decision; so, by making statin-taking seem commonplace, everyday medication practices and casual talk about them support the decision to take statins.

### **How do decisions about regular medication influence everyday medication practices?**

In discussions of shared decision-making, questions about the interaction between deciding to take medication and actually taking it are generally elided; the cognitive work of making up one's mind and the material work of accomplishing daily pill-taking are discussed separately. To understand how the two interact, it is helpful to cast the cognitive process as just one element of a discursively-informed social practice that produces a decision, defining a decision as a story about the right thing to do.

The same normative discourse that makes it "*right*" to take statins extends to shape the material practice of taking them: the tacit assumption is that responsible citizens make sure they take necessary medication. Surfacing this assumption, most participants' describe successfully enacting pill-taking; very few volunteer that they struggle to remember their pills, or accidentally omit them. Julie, who takes other longterm medication although not statins, is unusual in this respect:

*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...*

Her husband David does take statins. But instead of presenting the need to take pills as "*controlling [his] day*", he talks about the "*regimental*" control he exerts over his pill-taking:

*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]*

David presents this as a simple, single-handed accomplishment, but Julie's correction (and his accepting laugh) highlights that this control is accomplished through interactions with her as well as the "weekly box". 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; 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" – but most participants present remembering and reminding as something that is primarily women's work, as has been reported elsewhere [eg Langstrup 2013]. Wendy makes this explicit in an interview with her husband Peter, a statin-taker. She 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.*

This excerpt sheds light on the way a decision drives the material work of pill-taking:

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.

Once taking pills is accepted as the right thing to do, presenting oneself as successfully accomplishing regular pill-taking is central to participants' portrayal of themselves as competent and sensible. This portrayal is not undermined by acknowledging that carrying out daily medication practices is shared work, involving significant others as well as non-human technologies. For instance, Susan and her husband, Will, give no indication that their reliance on various people and technologies requires justification; they appear comfortable presenting

an account of their highly-collaborative medication practices. Describing how the pharmacy delivers pills to their home on the appropriate days and sets up devices to remind them what to take when, Susan shows the interviewer her spaceship-shaped timer device, alongside Will'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.*

Other participants reported more transformative work on the technologies that travelled between health settings and the home. Ted and his wife Hazel, for instance, explain how they modified the drug information sheets supplied by the hospital, by transcribing the regime in a format that they found easier to follow.

*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.*

In similar vein, others 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.

Importantly, no purely cognitive deciding process is visible in these statin-takers' accounts. For example, 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 says he cannot remember when this was in relation to other events. Such processes no doubt occur, but they leave few traces in everyday medication practices. 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. Rather, cognitive decision-making is carried on within a dynamic web of social practices which integrates the processes of deciding and doing.

## **Discussion**

Our findings inform a new framing of “deciding”, shedding light on the way deciding to take regular medication articulates with taking it regularly. Widely-used models of decision-making portray a decision as a relatively static object, produced by a predominantly cognitive process; the way this object influences action is left in a black box. To open this box we use our findings in two ways, first contrasting them with the findings of other empirical studies of medication decisions, and then relating our account to the growing body of research about the way people attend to their health at home.

Unlike many other studies of how people come to make medication decisions (see, e.g. Benson and Britten [2002], Pound et al [2005], Crinson et al [2007]), we found no evidence that participants engage in weighing options and choosing between them, and amongst statin-takers, no evidence of deliberation. A possible explanation for this discrepancy concerns a difference in methodological approach, rooted in the distinction between studying rationales for a course of action and reasons for it. Asking interviewees why they decided to take (or to decline) medication is liable to elicit a collection of rational, sensible-seeming answers that may have little bearing upon everyday medication practices. Instead of taking interview data as a stable reflection of reasons for taking or not taking medication, we use them as a source of clues about the discursive framings that make sense of what is said. Additionally,

recruiting in community settings and interviewing people informally at home, rather than through or in general practice surgeries (as in Crinson et al's [2007] study, for instance) may be less likely to elicit the more rational framings of risk assessments.

Interviewing at home, particularly in the couple interviews [Polak and Green, 2015], also enabled us to observe participants constructing and presenting an account of their health and health behaviours. This use of a methodological lens focused on stories and self-presentation is advocated by Radley and Billig [1996] in their exploration of health talk in the context of chronic illness. Building on Radley's [1989] work on the social constraints that inform adjustment styles, Radley and Billig describe their approach as underpinned by an ontological focus on "the activity of accounting" in interview talk, rather than a focus on the beliefs presumed to lie behind this activity. In using this approach in our study, we have attended to "accounting activities" including those of presenting oneself as "doing the right thing", rather than assuming these accounts reflect any underlying purely-cognitive "decision making". This has helped account for the asymmetries in our data between the accounts of those who were taking and those not taking statins.

Establishing "the activity of accounting" as our primary object of study is a useful first step towards situating "deciding" within a web of discursively-informed household activities.

Taking longterm medication is one of a collection of regular activities through which people take care of themselves. In our data, these activities include food preparation and serving, and bed time routines. Various different theoretical framings are used to study these activities.

For authors such as Corbin and Strauss [1985], Pickard and Rogers [2012], and Vassilev et al [2011], the central object of study is the work involved in living with a longterm condition.

This work is widely identified as collaborative, a feature emphasised by accounts focusing on social networks (for instance Cheraghi-Sochi et al, 2015) and evidenced throughout our data.

In addition to multiple health-related interactions with people, our data also indicate the salience of two other groups of interactions: interactions with technologies, and interactions unrelated to health. The role of biomedical technologies (such as CHD risk algorithms, cholesterol testing, or pharmaceuticals) in creating the conditions for cognitions (or ‘beliefs’) about coronary heart disease has been discussed by Saukko et al [2012]. Here, we show that statin-takers describe their pill-taking as supported by more mundane technologies, and as embedded within everyday routines. These findings could be understood in terms of care infrastructures. Langstrup [2013], for instance, proposes this approach for understanding the way chronic disease management is carried on at home; she describes the embedding of health-related practices within everyday household routines, something that our findings also evidence. Weiner and Will [2018] use the concept of care infrastructures to think about home blood pressure monitoring, specifically looking at the way it is practised by people who acquire their own monitors and do not identify themselves as having a medical condition. This focus enables Weiner and Will to extend their analysis beyond the confines of accounts that consider care infrastructures or shared work in the context of “chronic illness”; a similar extension is helpful for looking at statins, which are offered to people who are not ill and may not identify themselves as having “a condition” [Polak, 2016].

Like Langstrup, Hodgetts et al [2011] and Dew et al [2014, 2015] draw on data about medication use at home to portray medication practices as embedded within everyday material routines. Additionally, these authors foreground the discursive framings that shape and make sense of medication use; Hodgetts et al describe “the emplacement and use of medications ...as being implicated in processes of identity”, relating this finding to Radley’s [1989] work on adjustment styles in people with chronic illness, while Dew et al [2015] highlight the salience of moral discourses within household medication practices. [Polak, 2017] explores the morally-coloured identity work people do to reconcile regular pill-taking

with “not being a pill-taker”, work that involves calibrating and negotiating the multiple discourses and resources identified by Will and Weiner [2013, 2014] as informing talk about “healthy living”. In the findings presented above, there is no sign that participants’ identity as competent medication users is compromised by their accounts of the collaborations medication use requires. This is an interesting difference from Lumme-Sandt and Virtanen’s [2002] finding that individuals in focus groups discussing medication use worked to present themselves as “a person who can cope with one’s own medication”, not even collaborating with their spouse; in contrast, our participants describe sharing medication work in ways that suggest that such collaboration is no threat to moral adequacy.

Normative discourses are widely visible in our account of reciprocal interactions between doing something and deciding to do it: everyday material routines play a part in establishing statin-taking (for example) as “*commonplace*” and hence “*the right thing to do*”, while the same discourse that makes sense of this “deciding” process also shapes everyday medication practices. Statin-taking, then, is carried on through a discursively-informed web of household practices which includes not only material practices but also performative ones. For people to take longterm medication, this web must have two products: the material enactment of regular medication-taking; and a presentable account in which such medication-taking is “*an idea...one can live with*”.

## **Conclusion**

In the context of decisions about longterm preventive medication, we present an empirically-grounded critique of cognitive models of decision-making. Cognitive models failed to explain key asymmetries in our data between those who did and those who did not end up taking statins. To construct an alternative to such models we have considered “deciding” and “doing” together, identifying two-way interactions between them. Our model shifts cognition

out of the limelight: instead we foreground the activity of accounting for what one is doing, and the often-tacit discourses that inform this activity. Decisions about long term medication are not just distributed across time and space; they are also deeply embedded in both the discursive practice of accounting and the material practices of taking medications.

## **References**

- Benner, J. S., Glynn, R. J., Mogun, H., Neumann, P. J., Weinstein, M. C., and Avorn, J. (2002). Long-term persistence in use of statin therapy in elderly patients. *JAMA*, 288(4), 455-461. doi: 10.1001/jama.288.4.455
- Benson, J., and Britten, N. (2002). Patients' decisions about whether or not to take antihypertensive drugs: qualitative study. *BMJ*, 325(7369), 873. doi: 10.1136/bmj.325.7369.873
- Charles, C. and Gafni, A. (1997). Shared decision-making in the medical encounter: what does it mean? (Or: it takes at least two to tango). *Social Science and Medicine*, 44(5), 681-692.
- Cheraghi-Sohi, S., Jeffries, M., Stevenson, F., Ashcroft, D.M., et al. (2015) The influence of personal communities on the self-management of medication taking: a wider exploration of medicine work, *Chronic Illness*, 11, 2, 77–92.
- Corbin, J. and Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8(3), 224-247. doi: 10.1007/bf00989485
- Crinson, I., Shaw, A., Durrant, R., De Lusignan, S., & Williams, B. (2007). Coronary heart disease and the management of risk: Patient perspectives of outcomes associated with the clinical implementation of the National Service Framework targets. *Health, Risk & Society*, 9(4), 359-373.
- Dew, K., Chamberlain, K., Hodgetts, D., Norris, P., Radley, A., and Gabe, J. (2014). Home as a hybrid centre of medication practice. *Sociology of Health and Illness*, 36(1), 28-43.

- Dew, K., Norris, P., Gabe, J., Chamberlain, K., and Hodgetts, D. (2015). Moral discourses and pharmaceuticalised governance in households. *Social Science and Medicine*, 131(0), 272-279. doi: <http://dx.doi.org/10.1016/j.socscimed.2014.03.006>
- Dowell, J., and Hudson, H. (1997). A qualitative study of medication-taking behaviour in primary care. *Family Practice*, 14(5), 369-375. doi: 10.1093/fampra/14.5.369
- Eborall, H., and Will, C. M. (2011). 'Prevention is better than cure, but...': Preventive medication as a risk to ordinariness? *Health Risk and Society*, 13(7-8), 653–668.
- Edwards, M., Wood, F., Davies, M., and Edwards, A. (2013). 'Distributed health literacy': longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. *Health Expectations*. doi: 10.1111/hex.12093
- Elwyn, G., and Miron-Shatz, T. (2010). Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations*, 13(2), 139-147. doi: 10.1111/j.1369-7625.2009.00572.x
- Elwyn, G., Lloyd, A., May, C. et al (2014). Collaborative deliberation: A model for patient care. *Patient Education and Counseling*, 97(2), 158-164. doi: 10.1016/j.pec.2014.07.027
- Hodgetts, D., Chamberlain, K., Gabe, J., Dew, K., et al. (2011) Emplacement and everyday use of medications in domestic dwellings, *Health & Place*, 17, 1, 353–60.
- Horlick Jones, T. (2011). Understanding fear of cancer recurrence in terms of damage to 'everyday health competence'. *Sociology of Health and Illness*, 33(6), 884–898. doi: 10.1111/j.1467-9566.2010.01325.x

Jackevicius, C. A., Mamdani, M., and Tu, J. V. (2002). Adherence with statin therapy in elderly patients with and without acute coronary syndromes. *JAMA*, 288(4), 462-467. doi: 10.1001/jama.288.4.462

Langstrup, H. (2013) Chronic care infrastructures and the home, *Sociology of Health and Illness*, 35, 7,1009–22.

Lau, S. and Kriegbaum, M. (2018) Medication non-adherence in the context of situated uncertainty: Moving beyond simple, dichotomous approaches, *Research in Social and Administrative Pharmacy*, 14(8), 742-748

Lumme-Sandt, K. and Virtanen, P. (2002) Older people in the field of medication *Sociology of Health & Illness* 24 (3), 285–304

Marcum Z.A, Sevick M.A, Handler S.M. (2013). Medication nonadherence: A diagnosable and treatable medical condition. *JAMA*, 309(20), 2105-2106. doi: 10.1001/jama.2013.4638

Montori, V. M., Gafni, A., and Charles, C. (2006). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations*, 9(1), 25-36.

Nettleton, S. (2004). The Emergence of E-Scaped Medicine? *Sociology*, 38(4), 661-679. doi: 10.1177/0038038504045857

NICE (2014) Clinical Guideline 181. Cardiovascular disease: risk assessment and reduction, including lipid modification. <https://www.nice.org.uk/guidance/CG181/chapter/1-Recommendations#lipid-modification-therapy-for-the-primary-and-secondary-prevention-of-cvd-2>



- NICE (2019) Making decisions about your care. <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/making-decisions-about-your-care>
- Pickard, S. and Rogers, A. (2012). Knowing as practice: Self-care in the case of chronic multi-morbidities *Social Theory & Health*, 10(2), 101-120.
- Polak, L. and Green, J. (2015) Using joint interviews to add analytic value, *Qualitative Health Research*, 26(12) 1638–48.
- Polak, L. (2016) Current conditions or future risks: Certainty and uncertainty in decisions about statins, *Health, Risk and Society*, 18(3–4) 153–67.
- Polak, L. (2017) What is wrong with ‘being a pill-taker’? The special case of statins, *Sociology of Health & Illness*, 39(4), 599-613.
- Pound, P., Britten, N., Morgan, M., Yardley, L., Pope, C., Daker-White, G., and Campbell, R. (2005). Resisting medicines: a synthesis of qualitative studies of medicine taking. [Review]. *Social Science and Medicine*, 61(1), 133-155. doi: 10.1016/j.socscimed.2004.11.063
- Radley, A. (1989). Style, discourse and constraint in adjustment to chronic illness. *Sociology of Health and Illness*, 11(3), 230–252.
- Radley, A., and Billig, M. (1996). Accounts of health and illness: dilemmas and representations. *Sociology of Health and Illness*, 18(2), 220-240.
- Rapley, T. (2008). Distributed decision making: the anatomy of decisions-in-action. *Sociology of Health and Illness*, 30(3), 429-444. doi: 10.1111/j.1467-9566.2007.01064.x
- Saukko, P. M., Farrimond, H., Evans, P. H., & Qureshi, N. (2012). Beyond beliefs: risk assessment technologies shaping patients’ experiences of heart disease prevention. *Sociology of health & illness*, 34(4), 560-575.

Stevenson, F. A., Barry, C. A., Britten, N., Barber, N., & Bradley, C. P. (2000). Doctor–patient communication about drugs: the evidence for shared decision making. *Social science & medicine*, 50(6), 829-840.

Vassilev, I., et al (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness*, 7(1), 60-86. doi: 10.1177/1742395310383338

Weiner, K. and Will, C. (2018) Thinking with care infrastructures: people, devices and the home in home blood pressure monitoring. *Sociology of Health & Illness* Vol. 40 No. 2 2018 ISSN 0141-9889, pp. 270–282 doi: 10.1111/1467-9566.12590

Will, C. M., & Weiner, K. (2013). Do-it-yourself heart health? ‘Lay’ practices and products for disease prevention. *Health Sociology Review*, 22(1), 8-18.

Will, C. M., & Weiner, K. (2014). Sustained multiplicity in everyday cholesterol reduction: repertoires and practices in talk about ‘healthy living’. *Sociology of Health and Illness*, 36(2), 291–304.