

# The Discursive Construction of Prophylactic Medicine Taking for People with Asthma: Interactional Issues and Moral Discourses

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## Abstract

Since the 1970s research on how people take, or “adhere” to prophylactic medications, has been dominated by individualistic approaches emphasising the role of attitudes in explaining adherence, with limited predictive success. Such limitations may be related to a restricted conceptualisation of talk about medicine taking as an accurate representation of individuals’ attitudes. Using asthma as a case example, this thesis explored whether we can more productively view such talk as social action reflecting the interactional and social conditions in which it is produced. This enables us to examine interactional issues with specific influence on everyday decisions about medicine taking. Key amongst these issues are likely to be moral discourses of illness management.

Using ideas and tools associated with Discursive Psychology and Linguistic Ethnography, the author examined a range of data sources for how moral discourses of asthma management structured talk of people with asthma in face-to-face interview and focus group settings. Participants could be seen to deploy a range of rhetorical devices to justify medicine taking, positioning versions of their asthma management, views and themselves within a range of moral discourses that can be seen to circulate different social spaces.

Building on Goffman’s term “performance,” these findings indicated that people’s talk about medicine taking can be seen as transference of linguistic resources across contexts, manifested in different interactions. The “meaning” of performances is therefore a result of how different criteria, set up within interactions about illness management, match available resources deployed by individuals with chronic illness. These findings suggest that rather than seeing lay-professional discussions of medicine taking as being about persuading people to adopt particular attitudes, this approach allows us to see how mutually-agreed treatment decisions may, instead, require us to identify appropriate linguistic resources for facilitating discussion of patients’ everyday concerns about illness management, within that interaction.

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Qualitative Health Research article

CD containing full transcripts of interviews quoted within main text

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## **Chapter One**

### **Background to Research Investigating the Discursive Construction of Talk about Prophylactic Medicine Taking**

Since the 1970s research on how people have taken prophylactic medications has been dominated by individualistic approaches, with limited success for helping predict what people will do. Such limitations may be related to a conceptualisation of talk about medicine taking as providing an accurate representation of individuals' attitudes or beliefs. Taking asthma as a case example, the study reported here investigated what happens if we view that talk in a different way, as a form of social action. What different knowledge is produced and how can this knowledge be used to treat people with asthma and potentially other people with chronic illness?

This introductory chapter will set the scene for such a study of talk about asthma prophylactic medicine taking. This will begin by providing a brief overview of work done since the 1970s which has largely attempted to explain and predict the decisions that people make about taking prophylactic medications. It will focus on the possibility that notions of individual attitudes may be problematic because of assumptions about how talk has been understood in generating those attitudes. It will then specify what assumptions about talk underlie individualistic approaches, the problems with these assumptions and describe research that represents landmarks in how prophylactic medicine taking has been understood.

Questions raised about the usefulness of the concept of attitudes in other fields helps us to see why attitudinal research may have struggled to predict prophylactic medicine taking behaviour. Such questions reflect the view that any constructed relationship between behaviour, attitudes and talk, will be an artefact of academic practice rather than an accurate representation of human psychology and behaviour. This work will be used here to argue that if we want to gain a more robust appreciation of talk about medicine taking then we must question the core assumptions underpinning attitudinal research on prophylactic medicine taking and then provide alternative assumptions upon which to construct our knowledge of this subject. This will be the topic of the following section, providing a marker for how the distinctive approach taken in this study differs

from approaches commonly adopted until now. It is this new approach, which will frame an exploration of how talk about medicine taking can be seen as social action, and, through observing the effects of this action, reveal how speakers reproduce and create discourses of health, illness and disease in the accounts that they offer to others. There is some literature that shows people using talk about health and illness to present themselves in particular ways and that, instead of viewing such talk as a neutral account of individual's private beliefs, to better understand the issues that influence medicine taking on a daily basis, this talk should be framed as a form of moral practice.

In examining an example from a discursive psychological approach to understand talk about chronic fatigue syndrome, this moral practice can be seen to allocate blame and accountability for health outcomes, which are situated interactionally and historically within moral discourses of health and illness. To understand talk about asthma prophylactic medicine taking, examining both the interactional and historical properties of this talk may be fruitful by enabling a richer understanding of what happens in these interactions and how they might reflect decisions that people with asthma make about managing their condition.

In constructing a theoretical argument for how talk about medicine taking might be studied differently to earlier approaches, this research is itself situated within an historical context. Through conducting this study, I developed an awareness of my own construction of the data reported here and this led to some important changes in how the research proceeded, which are then summarised within an account of the development of this research. The chapter will conclude with a synopsis of thesis chapters.

This research addressed three key questions:

- How is talk about asthma management and medicine taking constructed with people who are not taking prophylactic asthma medications as prescribed?
- What role do moral discourses play in constructions of medicine taking by people with asthma and what does this say about the objectives of asthma policies and guidelines?
- How may discourse-related insights help us understand the limitations and achievements of a discursive psychological approach in understanding talk about medicine taking?



Answering these questions will provide new insights into the production of talk about medicine taking for people with asthma but also more generally for people with chronic illnesses. The potential problems for understanding decisions about medicine taking within an individualistic framework need to be resolved by understanding the process of constructing reported attitudes, perceptions and beliefs which shape how people take prophylactic medications. Seeing how accounts of medicine taking behaviour are influenced by different interactional issues, particularly moral discourses manifested in concerns of blame and accountability, may help to identify how different discourses constrain or facilitate what people say about their illness management. This will contribute importantly to how knowledge about medicine taking behaviour is formulated, by suggesting alternative ways to conceptualise and so interpret talk about such behaviour and methods. This knowledge can be applied to communication with patients in health care settings. If healthcare professionals can be more attuned to the discursive construction of talk about medicine taking and the role of morality within that talk, then they may come closer to the issues that more intimately influence decision-making about medicine taking in the daily lives of people who live with chronic illnesses. Recognising the interactional and moral dimensions of talk, may enable doctors, nurses and patients to reach more collaborative decisions about managing illness.

### **Overview of Adherence Research since the 1970s**

Prophylactic medications are now the first line of treatment in asthma prevention. The leading organisation and collaborator with the World Health Organisation promoting asthma control worldwide, the Global Initiative for Asthma (GINA) (2009), declares that *“the goal of asthma treatment, to achieve and maintain clinical control, can be achieved in a majority of patients with a pharmacologic intervention strategy developed in partnership between the patient/family and the health care professional”* (p. 57).

Achieving and maintaining asthma control is therefore seen as being about finding the appropriate medication. This is commonly a prophylaxis, typically a corticosteroid inhaler, which requires the person with asthma to take once or twice a day to achieve optimum asthma control. Understanding what influences people’s ability or willingness to comply or “adhere” to this medical advice, has preoccupied researchers for the last thirty five years although the realisation and attempts to understand why patients do not

follow medical advice date back as far as Hippocrates (Trostle, 1988, 1300). Traditionally, and still common, the term “compliance” denotes people taking and not taking prophylactic medication as prescribed. However, more recently, the term “adherence” has been used, to avoid the negative connotations associated with compliance. Even more recently the term “concordance” has emerged, which although not referring to medicine taking *per se*, symbolises mutual agreement, or “harmony” between doctor and patient (Royal Pharmaceutical Society of Great Britain, 1997). The term adherence rather than compliance is used in this thesis as the implications of this ideological and discursive shift, in understandings of the relationship between doctors and patients with asthma, lies at the heart of this study.

Poor adherence to prophylactic medications remains an important issue for the NHS and in asthma is described as a “significant burden” accounting for a large proportion of the costs of asthma (Barnes, Jonsson, & Klim, 1996). This is despite the investigation of nearly 200 potential barriers to adherence (Donovan, 1995; Royal Pharmaceutical Society of Great Britain, 1997) and the use of numerous models to predict adherence behaviour (Christensen, 2004). Systematic reviews of literature post-1970s research on adherence to treatments has found such work to have little success in predicting adherence to prophylactic medications (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Associated interventions have also proved inconsistent and difficult to generalise (Haynes et al., 2005; Peterson, Takiya, & Finley, 2003).

The majority of attempts to achieve the goal set out by GINA have focused on identifying the different variables that reduce people’s ability or willingness to take medication regularly. Research has focused on components of medications, individual patient or doctor characteristics, the doctor-patient relationship, disease features, the referral process and factors within consultations. The variables considered to have the greatest influence on adherence and shown to correlate with adherence are beliefs about medications and medicine in general (Ponieman, Wisnivesky, Leventhal, Musumeci-Szabo, & Halm, 2009; Roberson, 1992; Royal Pharmaceutical Society of Great Britain, 1997). Researchers have often drawn on theories from traditional psychology to explain the connection between beliefs and adherence to treatments, using and developing Social Cognition Models (SCMs). The most well-known of these is the Health Belief Model (Becker & Maiman, 1975) which constructed a direct relationship between the patient’s belief about their disease and treatment with their adherence behaviour.

However, alternative models also exist which either build on the Health Belief Model or contend that different aspects of the individual better predict adherence (Christensen, 2004). Consequently, no one model is regarded as the most predictive of adherence to treatments.

Other individual patient characteristics investigated to date as potential indicators of adherence have included personality, gender, age, sex, marital status, social class, disability and psychosocial factors (Harrison, 2005; Vermeire et al., 2001).

More recently, greater account has been taken of patient perspectives on health and illness which go beyond the specifics of the condition and medications (DiMatteo, 1994; Donovan, Blake, & Fleming, 1989; Naidoo, Dick, & Cooper, 2009; Stockwell & Schulz, 1993) and there have also been other studies that have attempted to understand adherence within a cultural context (Sankar, Luborsky, Schuman, & Roberts, 2002).

This shift has been seen in asthma research on adherence to medications which has attempted to move beyond a focus on individual characteristics to understand asthma medicine taking in terms of relationships and within the context of people's everyday lives (Adams, Pill, & Jones, 1997; Buston & Wood, 2000; Prout, Hayes, & Gelder, 1999; Scherman, Dahlgren, & Lowhagen, 2002; Walsh, Hagan, & Gamsu, 2000). These studies, using a variety of qualitative methods, have provided alternative ways in which people with asthma make sense of their condition, incorporating insights that captured the experience of asthma rather than focusing solely on individual attitudes towards asthma or medications.

This increasing awareness of the need to understand how people live with asthma and other chronic illnesses in everyday life reflects other research seeing the doctor-patient relationship and communication as vital in enhancing adherence (DiMatteo, 1994). It is now common to place importance on improving communication style to better understand patient perspectives, providing appropriate information and educating patients about the nature of disease and the functions and effects of medications. However, a synthesis of qualitative studies of lay experiences of medicine taking (Pound et al., 2005) suggested that a key reason why people do not take medicines as prescribed is that people are concerned about the safety of medicines, arguing that people "resist" the use of medications. These concerns have been shown to be difficult to articulate within consultations (Barry, Bradley, Britten, Stevenson, & Barber, 2000), with patient's views of medications often being unknown to clinicians, demonstrating

an absence rather than presence of concordant decision making between clinicians and patients (Stevenson, Barry, Britten, Barber, & Bradley, 2000). Pound *et al* argue that the concept resistance indicates a coercive power dynamic between medical care and patients but also that patients actively engage with their medications. This argument, along with the realisation of the need to capture peoples' lived experiences of asthma, suggests that we may need to account for any such resistance when communicating with people about medicine taking, not only in clinical settings, but also in our use of research methods.

### **Gaps in Knowledge: Problems with Individualistic Approaches to Understanding Talk about Medicine taking**

The notion that people may resist the use of medicines indicates that people with chronic illness, when talking about medicine taking, may wish to present themselves in particular ways to enable such resistance. However, the idea of resistance to medicines as a function of talk about illness management is typically not reflected in the literature to date. In addition there is evidence that many healthcare professionals appear to place more importance on clinical perspectives of medicines rather than those expressed by families and friends, potentially limiting the opportunity for collaborative decision-making within consultations (Stevenson, Gerrett, Rivers, & Wallace, 2000).

Individualistic approaches to medicine taking assume that what people say about medicine taking and chronic illness management, in research interviews, questionnaires or doctor-patient consultations, accurately represents a specific attitude, perception or belief that the person holds about health, their condition or a medication. The "attitude" is said to exist in a real sense which can be seen to be distinct from other attitudes or beliefs that the person also holds. As this attitude is seen as "owned" by the speaker, it is also viewed as relatively stable across a range of social situations. The functions of talk are therefore marginalised within this framework as is the role of context in shaping those attitudes. Context is commonly viewed as distinct from attitudes, seen as another variable that modifies decisions about medicine taking while not affecting the attitude itself.

However, there is research on health (Crossley, 2002; Gillies & Willig, 1997) and beyond (Gilbert & Mulkay, 1984; Potter & Wetherell, 1987) that provides evidence of

attitudes changing even during the same interactions. Crossley, in her study of views of health and illness, used focus groups based on a social constructionist methodology to explore the co-constructed nature of beliefs between individuals. She highlighted how attitudes of responsibility were quickly replaced by attitudes of resistance when she circulated health promotion leaflets. A social cognitive interpretation of this contradiction would be that “actual” individual attitudes were biased by the context of the focus group. In contrast, a social constructionist perspective might argue that reported attitudes existed as part of a process of mutual construction between the individual members and were constructed with reference to issues of blame and accountability within the context of the group’s interactions. Crossley’s individuals drew on cultural understandings of health and illness in apportioning blame and accountability and in doing so managed their attitudes, beliefs and identities, the key issues at stake within the interaction. This suggests that attitudinal approaches to adherence exclude important information about the changeability of attitudes within interactions which may undermine attempts to categorise those attitudes. Associated interventions aimed at changing medicine taking behaviour may therefore be inappropriate as they may be based on an attitude that does not accurately represent how people view their condition.

If attitudes towards issues of health and illness can be seen to change within interactions then we have to ask: what is an attitude? Is it appropriate to use this concept in understanding talk about prophylactic medicine taking? If not then what is an alternative way to understand this talk and what new sort of knowledge does this provide? The following section will address the first two questions by unpicking the assumptions that underpin the notion of the individual “attitude”, “belief” or “perception” which have been used to generate the epistemology relating to the decisions that people make about medicine taking. In addressing the third question, the approach to be taken in this thesis to understanding talk about prophylactic medicine taking will be presented.

### *Core assumptions about talk in attitudinal research on adherence*

Four basic assumptions underpin the attitudinal research on adherence: the notion that individuals hold a fixed attitude about health and medicine that is stable across different contexts; the idea that these attitudes can be elicited through appropriate research methods; the idea, that, once elicited, measured attitudes can be used to predict and

explain prophylactic medicine taking behaviour; and the view that social, cultural and situational issues are separate contextual factors external to our attitudes. These assumptions are fundamental to the types of knowledge that are produced or, importantly, missed about people and medicine taking. The following research extract on asthma medication adherence provides an example of the connection argued for between individual utterance, internal cognitive state and behaviour in most adherence research undertaken since the 1970s.

In a study of beliefs about asthma and self-management behaviours, Halm, Mora and Levanthal (2006) conducted an “interviewer-administered survey” which included the primary question “Do you think you have asthma all of the time, or only when you are having symptoms?” Respondents were categorised as having either one of these attitudes and to seek any association with beliefs about the importance of using prophylactic medications. Halm *et al* found that the “no symptoms, no asthma” belief was negatively associated with beliefs about always having asthma, having lung inflammation, or the importance of using inhaled corticosteroids, and was positively associated with expecting to be cured. The “no symptoms, no asthma” belief, or “acute disease belief” was also associated with one-third lower odds of adherence to inhaled corticosteroids when the person was asymptomatic.

The title of the article by Halm *et al* clearly asserts the link between talk, belief and behaviour: “No Symptoms, No Asthma: The Acute Episodic Disease Belief Is Associated With Poor Self-Management Among Inner-City Adults With Persistent Asthma”. It concludes that: “The single question ‘Do you think you have asthma all of the time, or only when you are having symptoms?’ can efficiently identify patients who do not think about or manage their asthma as a chronic disease” (p. 579). Talk about asthma can be clearly seen here as unproblematic in its production and in its access to the required belief about asthma. Furthermore, whilst presented as an association, the attitude is implicitly presented as a key variable in causing poor self-management of asthma as seen from the authors’ perspective. The objectivity of these findings is authenticated through the use of detailed data collection techniques with standardised questions, demographic tables detailing the participant’s representativeness of the broader population and the use of statistical analyses. However, the simplicity of the connection between talk and beliefs and the complete absence of discussion of context in how talk is produced is striking. The message in this research is that if we want to

find out who has the “wrong” attitude and therefore who we need to educate we just need to ask.

### **Deconstructing the Assumptions of Attitudinal Research on Adherence**

The study by Halm *et al* study builds upon research that also constructed such a relationship between individual talk, cognition and behaviour, manifested in the modelling of this theoretical relationship. The social cognition models that have been produced in the last 35 years represent formal attempts to predict and explain a range of health behaviours using the basic tenets that Halm *et al* propose. It is within these models where we can see how the complexity of the individual in a social world is managed by a scientific paradigm that places the individual at the heart of its epistemology.

The analysis of scientific talk by Gilbert and Mulkay (1984) is a useful tool to help deconstruct the assumptions of social cognition models. Their study is one of the key influences on the development of discursive psychology, a methodology which is foundational for the approach taken in this study. Their analysis is helpful to draw on in examining social cognition models, both for its explanatory power and for marking the key point of departure from previous adherence research.

Gilbert and Mulkay interviewed 34 scientists working in the field of biochemistry. In doing so they were not interested in the “truth” of a scientist’s account but rather how the scientists themselves went about building “truth”. They found that the scientists they interviewed demonstrated two distinct ways of talking about their own and others work in their field, referred to as two distinct “interpretative repertoires”: empiricist and contingency repertoires. The interpretative repertoire (Potter & Wetherell, 1987) is a concept central to discursive psychology and refers to a higher-order analytical element that is repeatedly used by speakers to characterise or evaluate actions, events, or perhaps a particular position one might take on a particular topic. It occurs in a particular piece of talk to achieve particular functions and is identifiable by patterned styles and grammatical forms such as specific phrases, metaphors or figures of speech.

The empiricist repertoire identified by Gilbert and Mulkay involved statements of fact based on “the evidence”, which assert an objective account of “how the world is”. Here the researcher is constructed merely as observer of the object of analysis in the true

spirit of positivist scientific practice. In contrast, the contingency repertoire involves statements which explain “mistaken beliefs” about the same object and these errors were attributed to social factors such as failure to understand, personal vendettas, commitment to one’s own theories, dislike of the new theory as well as many more personal and so non-empirical barriers to objectivity. Gilbert and Mulkey found an asymmetry in scientists’ talk whereby the empiricist repertoire was always used in their own description of how they obtained their findings and hence their own theory about the object of analysis. In contrast the contingency repertoire was deployed to explain any alternative theoretical interpretation. Gilbert and Mulkey found this pattern so pervasive across scientific talk that every example of theory put forward as empirical was found to be explained away by another scientist with the contingency repertoire.

### ***Applying the analysis of Gilbert and Mulkey to social cognition models***

Although Gilbert and Mulkey focused specifically on scientists’ talk we can see how the same repertoires have been deployed in research papers on adherence to construct knowledge of talk about medicine taking. The connection between individual utterance, the notions of internal cognitive representation (attitude, belief, perception) and behaviour are widely constructed in attitudinal research on adherence as a unidirectional causal relationship, an epistemology which is presented on empirical grounds. That a theory should be presented as formulated on observable evidence within a scientific paradigm is of course not surprising. What is of interest however is how complexity in people’s talk and human behaviour is managed in this research, how the coherence of this essentially individualistic theory is maintained in light of the range of ways in which people talk and behave in relation to their health, illness and medicines. This is informative because it demonstrates how context is formulated and managed within individualistic approaches and the social cognitive framework. This will provide a key point of contrast to the approach taken in this thesis.

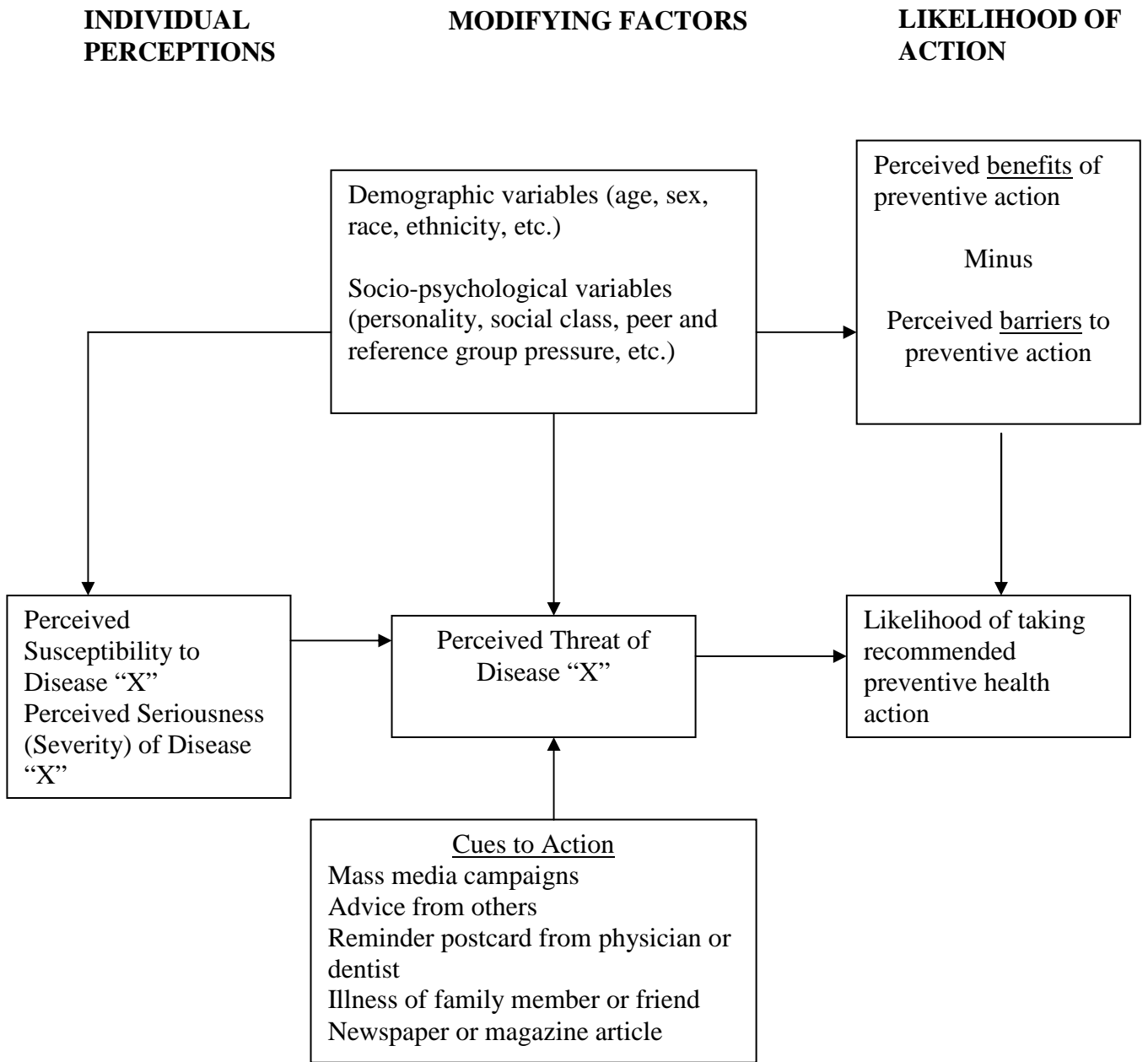
In the health belief model by Becker and Maiman (1975) (depicted in Fig. 1), which was the earlier model to be applied to asthma medicine taking, we can see how perceived susceptibility and seriousness of the disease are constructed as the core factors influencing the likelihood of action in the same way constructed by Halm *et al* thirty years later. In this model, individual perceptions are independent entities that are stable across all contexts. However, there are a list of demographic and socio-



psychological factors as well as “cues to action” that may modify a perception and action on any one occasion including age, sex, personality, peer group, newspaper article or chat with a friend. Importantly though, these variables are seen as outside the individual perception, a discrete, independent entity. This version of context constructs it as contingency, covering anything beyond the perception itself which can explain any utterance or course of action taken but which does not undermine the existence and explanatory power of the individual perception. As Becker and Maiman suggest: “While it is assumed that diverse demographic, personality, structural, and social factors can, in any given instance, affect an individual’s health motivations and perceptions, these variables are not seen as directly causal of compliance” (p.13).

In this view, context is seen as a separate variable that accounts for contingent deviation from the theoretical expectation. As it covers any action that a person may take concerning their health, the key theoretical link between individual perception and compliance remains intact. To deal with contradictions in the evidence, Gilbert and Mulkay found that scientists could often be seen to use a “truth will out device” (TWOD), (Potter & Wetherell, 1987, p.153) in their talk to argue that repeated application of a model or theory will triumph over contextual issues in the end. The problem for adherence research to date however is that this is yet to be proven.

Figure 1: The “Health Belief Model” as predictor of Health behaviour, Becker & Maiman 1975



### *The impact of social cognitive assumptions on research practice*

We can see the impact of these methodological assumptions not only in the theoretical model used to explain adherence behaviour but also in how this assumption regulates the methods routinely used to collect data, the type of data obtained, the results reported and any subsequent intervention. An important implicit assumption of social cognitive models is that attitudes, perceptions and beliefs reside internally within each individual. The way to access attitudes therefore is to focus on the individual and to treat data as unique to that individual. For example, the cross-sectional study by Horne and Weinman (2002) used questionnaires to explore the role of illness perceptions and treatment beliefs for people with asthma. They extended Leventhal's self-regulatory model (Leventhal, Diefenbach, & Leventhal, 1992) of illness perceptions to incorporate beliefs about treatment. The questionnaire is ideal in obtaining categorical, individualistic statements that can be assigned an "attitude" whilst data, (talk or free text comments on questionnaires) that do not specifically answer the questions, are not considered as data to be used for the primary analysis. Importantly, by directing the respondent to express their experience of asthma in a specific format, in this case by using the commonly applied Likert-type scale, the tool's sensitivity to any variation in individual attitudes is restricted. Indeed, any variation would present distinct difficulties for categorising a particular attitude and would challenge the assumption of a coherent attitude itself. The research of Horne and Weinman produces results reporting percentages of participants who express attitudes towards asthma and medications within a range of domains, for example how they view causes of their asthma (e.g. pollution), its duration "my asthma will last a long time," consequences "my asthma is a serious condition," the necessity for medication "my health depends on this medicine," side-effects "this inhaler is harmless." The intervention they go on to propose is therefore to modify perceptions and beliefs of asthma and medications through appropriate educational techniques. By presupposing that individuals have fixed attitudes, the tools used to collect it and the data that is produced will solipsistically substantiate the existence of such attitudes.

Applying the "empiricist" and "contingency" repertoires identified by Gilbert and Mulkay to social cognitive approaches, enables us to see how the core unit of analysis, the attitude, is deployed in research practice to produce an epistemology that provides sets of statements about the individual which are predictive of medicine taking

behaviour. The methods used to retrieve these data serve to reinforce this unit of analysis and the theoretical modelling that is produced forecloses any challenge to these fundamental principles by explaining context as contingency. This form of theoretical closure, reducing decisions about medicine taking to a finite set of attitudes and beliefs marginalises the importance of social factors such as relationships, family, work, constructing them as contingent, random events. In contrast the individual is presented as the core source of meaning, presumed to hold a discrete set of rational attitudes, perceptions and beliefs which are not random but consistent and largely fixed entities.

### **Assumptions of Discursive Psychology**

Of course, the analysis by Gilbert and Mulkay demonstrated their own aims and assumptions and those developed within discursive psychology. The same assumptions form the basis of this thesis and so need to be discussed here in three stages. Firstly, instead of trying to establish what the “truth” is in any account, Gilbert and Mulkay were more interested in what is achieved in talk; how versions of truth were constructed, argued and authenticated in the discourse of scientists, whilst undermining alternative versions and disclaiming any vested interest. From this view, talk about medicine taking is not about just conveying information that may reside “inside our heads” but is about trying to achieve something in that talk. Language therefore can be seen as performing an action. In the study of Gilbert and Mulkay study this could be seen for scientists attempting to uphold their own theories in their talk while discounting alternatives.

Secondly, as talk is seen as oriented towards social action, it will therefore change according to the functions and social conditions in which it occurs. Variability in people’s accounts is therefore seen as a manifestation of differing social conditions, not as a distortion of a cognitive state. Instead of debating the existence of a coherent internal representation called an “attitude” or a “belief” or a “perception”, the discursive psychologist argues that it is more appropriate to respecify attitudes as language that are constructed within and between individuals, groups, institutions and cultures at particular points in time. Talk takes place in social spaces and therefore is inevitably situated by the time and place in which it occurs. This means that instead of viewing the individual with perceptions and context as separate entities we can only understand perceptions when seen from within a social historical context.

Finally, and as an implicit implication of the first two assumptions, the view expressed about the object of thought and the object itself are inseparable. If talk is constructed in social spaces and those views can be seen to vary, then so can the definitions and descriptions of the objects that are used to convey those views. The issue of account variation has been discussed at length by Potter and Wetherell in their critique of attitudinal research (1987). They argue, through numerous examples, that a fundamental problem for attitudinal research is that evidence of variability in how objects are described demonstrates that the object of thought is inextricably linked to the attitude being expressed. This raises serious problems for the idea that people, in expressing an attitude are always referring to the same thing when expressing that attitude.

### *Applying discursive psychological assumptions to talk about health and illness*

As the assumptions of individualistic approaches have been seen to give rise to particular types of knowledge about the person with asthma and prophylactic medicine taking, so too can discursive assumptions be seen to produce their own type of knowledge. We can see how the discursive assumptions discussed here have been applied in other areas of health and illness research.

The following extract is from Horton-Salway's thesis (1998) on the discursive construction of chronic fatigue syndrome, or ME. Using a discursive psychological approach to analyse accounts of the onset and origins of illness, Horton-Salway demonstrated that the acceptance and recognition of ME as an organic condition, as opposed to "all in the mind" was a hugely contested area. People with ME did not merely provide an attitude towards ME in a way that may be considered accurate, inaccurate, or distorted in the cognitive sense. Instead, they were describing and explaining events in specific styles and with specific pieces of evidence to construct a particular version of reality. In this example we can see how Joe chose a particular description of events as evidence to support the idea that ME is a real disease.

34. Joe = I went swimming one week (.) you didn't feel up to it (.) then the  
35. following week  
36. Angela = you were alright weren't you?  
37. Joe =yeah and this ties in because it's now known that ME is caused by

38. er (.) an enterovirus which is a prime place to pick up an enterovirus is  
39. a swimming baths (.) it's also the classic(.) used to be the classic place  
40. to catch polio in the old days (.) hot summers (.) and I think with  
41. swimming (.) kids being in the bath all through the day (.) at the end of  
42. the day the water wasn't getting through the cleansing plant quick  
43. enough (.) I suspect if you'd gone first thing in the morning it would  
44. be absolutely spot clean (.) but er I suppose by the time we got there (.)  
45. I suppose the enteroviruses were still there (.) yeah (.) just unfortunate

(Horton-Salway, 1998, p. 174)

Horton-Salway argued that Joe was not just providing a neutral description of events to formulate this explanation of what caused Angela's ME. She showed how Joe blended the "classic" script of a polio story with Angela's personal narrative to add an authoritative voice to his argument. The key point being that Joe was showing that catching a virus in swimming pools was not an untested idea but was grounded in scientific evidence. Angela's visits to the swimming baths therefore positioned ME alongside polio and as recognisable as an organic disease. At the same time, the sequence of events constructed by Joe of an everyday mundane activity of going swimming positioned Angela as "unfortunate", Angela was therefore not to be blamed for having ME but was at the mercy of fate in the same way as people with polio.

This example illustrates that Horton-Salway's participants were managing important issues at stake around the very nature of a particular condition. Having what Horton-Salway called "authorship" of this illness could be seen to be critical in managing potential accusations of blame and accountability for the particular symptoms that people like Angela were experiencing. They were therefore not simply internal representations that were being communicated to the listener but were expressions that attended to the differing versions of ME that pervaded British society in the 1990s, a time when the meaning of this condition was hotly contested. Attitudes towards this illness are therefore better seen as a form of social action to manage these issues and ME, the object being described, as inextricably linked to that attitude. This type of social action is situated not only by the social historical context in which conditions like ME were being debated but, as Radley and Billig (1996) emphasised, also within the context of the interaction taking place. It is better, they argued, to view beliefs about health and illness as accounts given to others in particular situations. As people do so,

they deploy ideological themes to naturalise their versions of the world, in ways which serve the specific demands of the interaction itself. So, in the case of Joe and Angela, Joe used the classic case of polio as a vehicle to employ an interpretative repertoire of the “unfortunate” individual coming into contact with an organic virus to naturalise the causes of Angela’s symptoms and that of ME. This repertoire is therefore one which drew on a cultural explanation of illness which says that suffering from an organic condition is acceptable and excusable within British society at this point in time. By understanding this moral context we can see that the issue that was salient for Joe and Angela in daily life was whether they were responsible for Angela’s condition. This could have influenced whether Angela was viewed as a “bad patient” and whether she could gain easy access to particular treatments and services.

Horton-Salway’s example demonstrates that the accounts that people provide about health and illness can be seen to be influenced by how issues of blame and accountability are understood within any particular interaction. This type of moral talk has also been identified across a range of conditions and health-related behaviours, including smoking (Coxhead & Rhodes, 2006); infant feeding (Lee, 2007); AIDS and drug-use (Hassin, 1994); HIV and unprotected sex (Rhodes & Cusick, 2002); back (Lee-Treweek, 2001) and chronic pain (Werner, Isaksen, & Malterud, 2004); talking positively about cancer (Wilkinson & Kitzinger, 2000) including treatment decisions for cancer (Bishop & Yardley, 2004) and talk about medicine taking for older people (Lumme-Sandt, Hervonen, & Jylha, 2000; Lumme-Sandt & Virtanen, 2002). The accounts provided by people in this literature were historical in that the allocation of blame and responsibility within the reported interactions were influenced by how those versions came to be evaluated at that point in time and in that particular place. The different connections between health, illness and behaviour that were activated by the participants within those interactions were key influences on these evaluations. These were likely to be drawn from culturally-available explanations (Willig, 1999) of health, illness and behaviour that were circulated through discourse (both linguistic as well as other forms of discourse for example images of health used in health promotion campaigns) between people, groups, social networks, institutions and cultures. These discursive connections could be seen to link types of behaviour to particular states of health, not purely in terms of the physical consequences but importantly with an evaluation of that behaviour as something which was good or bad. They can therefore be seen as moral discourses of health-related behaviour that circulate in society and

blame and accountability will be allocated within interactions according to the moral frameworks activated within that interaction. If we can understand the moral context in which people talk about prophylactic medicine taking then we will have a firmer appreciation of the issues that are salient for people when they talk about the management of their condition and how blame and accountability may be distributed within healthcare, research and other interactions as a result.

Attending to moral elements of that context may well offer two particular advantages over individualistic approaches. First, in viewing talk about medicine taking as involving managing moral issues instead of articulating an attitude, we can see how these same issues may influence decisions people take about medicine taking and are also manifested in talk. Changing behaviour is then not about changing the individual attitude through education but instead about recognising the social situations in which issues of morality around illness management and medicine taking are relevant and in which people make decisions about medicine taking. Second, we can examine the potential consequences of particular types of talk for particular treatment decisions and follow-up of patients in clinical settings in ways which social cognitive approaches cannot do. Reported attitudes towards asthma and medicines and medicine taking behaviour are likely to be evaluated differently in different contexts. There are likely to be differing implications for how particular types of talk are categorised, in accordance with medical notions of appropriate behaviour regarding asthma management. How patients are evaluated in asthma consultations may well be influenced by how different accounts fit into clinical perspectives. From a medical perspective which maintains adherence to prophylactic medications as the ideal asthma management behaviour, understanding the role of morality in talk will provide insight into how patients may need to “perform” (Goffman, 1959) the correct attitude to gain access to particular treatments and how different types of accounts are likely to be categorised.

What has traditionally been conceived of as attitudes can instead be seen as moral practice. Discursive psychology shows us how versions of the self and behaviour are produced in talk to manage blame and accountability. What is at stake in these accounts therefore are competing versions of the self and behaviour which are judged from within a particular moral framework. Discursive psychology emphasises the creative and productive nature of interactional talk and as Radley has demonstrated the use of rhetoric in discussions of health and illness emphasise that cultural explanations are



produced through talk as people manage different dilemmas within interactions.

However, cultural explanations of health and illness are not only a product of particular interactions but have their origins in everyday life. Moralities can therefore be seen as regulating talk as well as being produced through talk. The production of particular cultural explanations, versions of the self and behaviour therefore have a spatio-temporal component beyond the interaction itself.

### *Defining talk, discourse and “attitudes”*

Having set out how talk was understood differently in the study reported here, to those that have previously studied adherence, notably reconceptualising talk as a social, rather than individual product, a definition of talk may be usefully introduced that can be applied within this alternative discursive framework. It is also important to distinguish between the use of “talk” and “discourse” in this study. In addition, having problematised the notion of an “attitude” some description of the use of this term in this thesis would be beneficial.

Discourse has two meanings in this thesis. The first meaning literally refers to the talk of participants. However, using the term “discourse” rather than “talk” is intended to firmly position that talk within the linguistic framework of this study. Talk is understood in many ways and the attitudinal approaches critiqued in this thesis view talk very much as belonging to the individual. Discourse in contrast, places that talk in a social space beyond the boundaries of exclusive individual construction. Where the term talk is used, it refers to a shared view of what is the raw data for many social scientists and which precedes any disciplinary manipulation. However, there are occasions where “talk” has been used, where “discourse” could be used instead. In these instances this has been done so to avoid confusion with the second use of discourse in this thesis.

The second definition of discourse is much more abstract and refers to the role of culture, history and power in the production of meaning. The work of Foucault (1972) is particularly illuminating in understanding this definition of discourse and how the production of meaning is regulated in society. Foucault argued that it is possible to identify sets of statements produced in talk and in text that have their origins in a particular way of understanding a part of the social world. These understandings are not isolated from society and history but are emergent through particular social conditions

and carry with them particular rules and ideologies of knowledge and beliefs. A discourse in this sense is a collection of related statements that have been formed by and through groups, social networks and institutions and which serve to reproduce this understanding. This study, and the topic of Chapter Two, will discuss how collections of statements about asthma management can be seen as deploying a “moral discourse of asthma management.” It will also discuss the origins of this discourse, how and whether it might regulate what people with asthma say about medicine taking and discuss the implications of this talk for people with asthma.

In this thesis the term “attitude” is used in two distinct ways: when written without quotation marks (attitude), it is used to reflect everyday taken-for-granted meaning, as is intended by those adopting this concept in individualistic and social cognitive approaches. In contrast, where “attitude” is used, a discursive critique of this term is being made which highlights the problems of adopting this term in understanding talk.

### *Applying discursive psychological assumptions to talk about prophylactic medicine taking*

Discursive psychological ideas have already been used to understand adherence to dietary regimens in diabetes (Peel, Parry, Douglas, & Lawton, 2005); exercise (McGannon & Mauws, 2000) and hormone replacement therapy (Hunter, O'Dea, & Britten, 1997; Stephens, Budge, & Carryer, 2002). This research has demonstrated how people can be seen to construct therapies in a variety of ways to perform particular interactional tasks, revealing concerns about treatments and the need for clinicians to take greater account of discourses beyond medicine that might influence patients' decisions. Applying discursive psychological assumptions to how people with asthma might talk about prophylactic medicine taking enables us to ask: what issues are being attended to in talk about prophylactic medicine taking? What is achieved in this talk? How is talk about asthma prevention situated by the social historical context in which it takes place and what role do discourses (abstract) of health and illness play in the accounts of medicine taking that people provide? Providing answers to these questions will provide insight into how people with asthma and perhaps chronic illness more generally wish to be understood. Their talk produces and reproduces ways of being in the social world, that carries with it evaluations of the reported attitude or version of events. This implies that if talk about medicine taking is a form of social action, aimed

at portraying ourselves in particular ways, then that talk is situated within a moral framework. Rather than categorising talk as reflecting an attitude that may need to be changed, the issue for researchers and healthcare professionals then becomes what are the moral properties that are produced in people's talk and what implications might this have for how people manage their condition?

### **Summarising differences in approaches to knowledge between individualistic approaches and discursive psychology**

Both individualistic and discursive approaches to talk about health and illness begin with assumptions that have an impact on the type of knowledge that is produced. In particular, social cognitive approaches, the predominant paradigm applied to explaining adherence, assume that people hold and are able to reliably report attitudes, beliefs or perceptions about a particular issue in health. This means that the speaker must consistently describe the same object of thought in expressing that attitude. Asthma, illness, disease, severity, health, medication etc are objects that are borne out of the biomedical paradigm which clearly depends on the objectification of these categories for clinical practice to be implemented. However, discursive psychology would argue that a difficulty arises when these same assumptions are applied to people's views of asthma and medication. As we saw with the work of Horne *et al* (2002) the research methods employed to access attitudes towards asthma and medications often restrict the possibility of picking up any variability in attitude and object description. Discursive psychologists, however, assume that variation is an inherent property of accounts and ask if and why objects such as asthma, medication and illness, might be described in particular ways at certain points but in a different way at other points in an interaction. The research methods this approach employs would attempt to facilitate rather than restrict variability.

Examining the talk of people with chronic illness has demonstrated that actions and what can be seen as attitudes relating to health, are often justified not just reported. This rhetorical work in talk suggests that the person's attitude, identity or version of events is at stake within the interaction taking place with the potential threat of competing, less desirable alternatives. Seeing talk about health and illness as affected by competing versions of the self, identity, knowledge, attitudes, places talk about health and illness within a moral framework. If talk about medication use orientates to different

moralties, then we cannot be sure that a particular attitude is being accurately articulated. This possibility raises doubts about the reliability of categorising talk about medications as representing a particular attitude that can then be used as a predictor of adherence. Situating talk about prophylactic medicine taking as having a moral agenda raises the need to discuss why morality might be a relevant concept to apply here. Why might this type of talk be value-laden and what do we mean when we talk about morality? This is the focus of Chapter Two but at this point it is now appropriate to provide a background, chronology and synopsis of the chapters within this thesis which will elaborate the key ideas introduced in this chapter.

### **Author's background and chronology to study**

The idea for the study reported in this thesis came about through my role as a Research Associate in the ELEVATE study, a large randomised controlled trial comparing the cost-effectiveness of two prophylactic medications for asthma. These medications represented the therapy typically prescribed for the prevention of symptoms, the inhaled corticosteroid and a prophylactic tablet called a Leukotriene Receptor Antagonist, or LTRA, which although available in the NHS, was rarely prescribed at this point. Participants were randomly allocated one of these two treatments and followed up for a period of two years using a mixture of questionnaires and breathing measurements. My task, whilst largely free for me to design, was initially to compare participants' perceptions of the two treatments and to use these insights to complement the main study findings regarding participants' reported "quality of life", "asthma control", prescription refill rates and NHS resource use. For example, if prescription refill rates for the LTRA tablet were higher than for the inhaled steroid, after patients had spent two years in the study, then reported perceptions of the treatment may be able to shed some light on the reasons for this difference and these data could therefore also be used to triangulate with quality of life and asthma control scores across the two groups. The design of this qualitative sub-study was therefore set within this methodological framework of measurement and follow-up. Participants taking part in interviews would be interviewed when entering the study and then interviewed a second and perhaps even a third time at intervals across the two year follow-up period.

However, the sub-study also had the potential to contribute to a broader understanding of prophylactic medicine taking. Patients' ability or willingness to "comply" or

“adhere” to regular prophylactic treatment has received much attention since the 1970s and is, as yet, largely unresolved. It was therefore appropriate for a study comparing perceptions of two different prophylactic medications would be set up within this existing literature on adherence to treatments. This was given even greater appeal as it presented an opportunity for me to test out two competing approaches to the issue of “non-adherence” to medications. The first of these came from the dominant methodology used to study patient adherence adopted since the 1970s, the social cognitive approach, which aims to elicit patient’s attitudes, beliefs and perceptions about their condition and their medications as a way to predict medicine taking behaviour. The second of these came from my own background as a psychology graduate from the Open University.

The design of the social psychological element of the Open University’s Psychology course particularly appealed to me as it raised the possibility that the same object of analysis can be understood in completely different ways, having extremely important implications for the members of society that these understandings affected. The object of analysis could be virtually anything in the social world: notions of intelligence; personality; identity; learning; education; relationships; health; racism; and the dynamics of group behaviour. The ontology and epistemology of social life was being called into question in ways which critiqued traditional individualistic models and conceptualisations of these objects, and extended the analytical focus beyond the individual to meaning constructed in social spaces.

The input of Wetherell and Potter to these course materials, offering such alternative conceptualisations of social life, had the most influence on my approach to this study (1987). In developing discursive psychology, Wetherell and Potter critiqued the notion of individual attitude and importantly its production in interactional talk. Rather than reflecting an individual’s internal cognitive state, Wetherell and Potter showed how talk about a social issues such as racism, can be seen to shift according to the demands of the interaction, thereby questioning attempts to pin down that talk as a coherent articulation of an individual’s attitude. Instead, they argued, we would be better off looking at how objects of analysis as “facts” are constructed by speakers themselves and examine the implications of those constructions. The re-specification of the meaning of interactional talk by Potter and Wetherell therefore offered a way to reconceptualise talk

about medicine taking which could then be set against the same assumptions of individualistic methodologies.

This study and this PhD thesis was therefore developed from an initial comparison of specific medications to become an examination of whether an alternative conceptualisation of talk about medicine taking might be fruitful in developing new insights about the decisions that people make about medicine taking. However, the design of this exploration was not neatly set up at its conception but, as I have described, was initially situated within the positivist paradigm of a randomised controlled trial comparing participants' perspectives at different time points. The early attempts to identify the interactional issues being managed in participants' accounts were therefore framed in this way and were implemented by attempts to identify the different ways individuals justified their medicine taking, their "accounting styles," which could be seen to persist across two different interviews. Data were obtained to meet these objectives and it was only through reflecting on these data, that the initial aims, assumptions and methods involved in identifying accounting styles were exposed as problematic in how they reflected the talk of participants, and moreover as methodologically incoherent with a discursive psychological approach. If talk is viewed as situated social action, then focusing on the individual and categorising that talk as having a particular style is more logical from within an individualistic rather than a discursive paradigm. Similarly, seeking persistence of an "accounting style" in two different time points represents an attempt at replication more appropriate within a positivist rather than discursive framework which embraces difference as evidence rather than replication in the phenomena it investigates.

It was following this reflective work that a different strategy was adopted that engaged more fully with context in which talk about medicine taking was produced. This was to analyse interactional sequences of face-to-face interviews in detail to identify how the properties of situated social action set out within the discursive approach of this study could be seen to be operating. These properties included evidence of how participants could be seen to manage issues of blame and accountability indicating a moral agenda in their talk which would therefore address the main issue of enquiry in this study.

However, this analytical work generated its own problems in that it became difficult to make claims about talk about medicine taking and the activation of moral discourses in

an interaction beyond that of the interviewer-participant dyads that were constructed. In addition, there was evidence that some participants did not justify their medicine taking at all. This raised the issue of how best to validate the findings from the interview data which was both new and methodologically coherent with the approach being taken in this study. By taking a broader view of context that went beyond the transcript of the interview itself it was possible to specify the social conditions in which participants could or could not be seen to be justifying their medicine taking, subject to pre-interview conditions being constructed through participation in the ELEVATE study. In addition, a new data collection strategy was adopted based on a different set of interactional conditions to the face-to-face interviews which could be used to examine whether moral discourses of medicine taking were activated by participants. This was done using a data-sharing focus group (Murdoch, Poland, & Salter, 2010) (published article attached as an appendix), presenting participants (of whom, all but one had taken part in face-to-face interviews) with anonymous vignettes developed from the data in face-to-face interviews. This group task provided different data in which we might see moral discourses of medicine taking being activated. In doing this, I was able to make stronger claims about the issues faced by people when discussing illness management and the role of morality within different interactional contexts which might also influence decisions about prophylactic medicine taking. This thesis and the chapters outlined here therefore reflect a chronology in the development of the study's design framework:

## **Synopsis of Chapters**

### *Chapter Two: Morality in Talk about Prophylactic Asthma Medicine taking*

This chapter sets up the rationale for investigating the role of morality in participants' accounts, building on the review of literature in Chapter One that identified how morality could be seen to be managed within interactions about health and illness. To further establish the rationale for a study examining morality, a review of literature was undertaken which demonstrated evidence that notions of morality have been linked with asthma throughout history and are still pertinent today. This literature review adopted a strategy of examining the language used about asthma in sources which appeared to represent the dominant conceptualisations of asthma at that point in history, not arguing that alternative conceptualisations were not available, but rather that those most widely

circulated were those most likely to inform clinical practice and everyday concepts of asthma and its management.

Reporting this evidence is therefore not intended to provide a fixed idea of the moral context of medicine taking, but rather to be used as a starting point for investigating the circulation of discourse to the talk of people with asthma. It will present possibilities for how moral discourses of asthma management have circulated through space and over time and which may influence current conceptualisations. These are used to evidence a cultural moral context which is likely to influence what people say about asthma medicine taking which was evident from a range of sources. This work is situated within broader evidence of how health and illness more generally have been informed by morality and a review of this evidence is included in Appendix D. It will be argued that examining the moral context that was likely to inform how people with asthma talked about medicine taking was therefore likely to be productive.

### *Chapter Three: Methodology and methods for investigating the discursive construction and role of morality in talk about prophylactic medicine taking*

Building on the rationale that there is a need to understand the interactional issues and role of morality in talk about medicine taking, this Chapter explains how this was done in this study, first constructing the methodology that was used and secondly the data collection methods that followed.

Three methodological strands were key in analysing interview and focus group data. The biggest influence was the discursive psychological (DP) approach of Potter and Wetherell already discussed in this chapter. It will be argued that a DP approach provided an ideal set of tools in which to examine the discursive construction and role of morality in participants' talk because a moral agenda can be seen as an implicit property of talk which is viewed as social action. In addition, the development of DP was borne out of a criticism of traditional social psychological concepts such as attitude, and so was a logical approach to apply to a similar critique made in this study. Using data from relevant literature, the properties of DP are discussed and how they can be applied to this study of talk about medicine taking. In doing so the relationship between structure and agency in the production of talk is raised and this discussion then leads to the second strand forming the methodology which comes from theories on the role and function of power. The assumptions about how abstract moral discourses of medicine



taking might structure the talk of participants are set out, using data which demonstrates a dynamic relationship between individual utterance and systemic discourse.

This then leads to a discussion of the final strand of this study's methodology which emerged from realising, through the analysis of interview data, that claims about the discursive construction of talk about medicine taking and the role of morality within that is not a straightforward process whereby the researcher merely observes and lifts the relevant meanings from the transcript. Instead, the author will suggest that the function and role of power in discussions about medicine taking need to be investigated in relation to interactors' access to linguistic and institutional resources and the contextual conditions that may be pertinent to those encounters. Analytical tools and ideas from Linguistic Ethnography (LE) (Rampton et al., 2004) will be described which enabled such investigation, suggesting ways in which interactor's resources and the contextual conditions of the interview data might be analysed. Details of the participants and the methods of data collection will then be set out, arguing how the different forms of data collected were appropriate to address the questions raised in this study.

#### *Chapter Four: Analysing Interview Transcripts to Evidence Interactional Issues and Moral Discourses in Talk about Prophylactic Medicine taking*

This chapter reports the analysis of face-to-face interview data to identify interactional issues and the role of morality in participant's talk about their asthma management. Following from the early attempts to identify accounting styles, the properties of talk about medicine taking are examined using extracts from the interview data. Based on those properties set out by Potter and Wetherell (Potter & Wetherell, 1987, pp. 32-55), participants' talk will be examined, demonstrating how talk about medicine taking may be viewed as a process whereby speakers need to manage different dilemmas in their accounts which orientate around the allocation of blame and accountability. This analysis will assess how identifying such evidence reconfigures our understanding of notions of individual attitudes about medicines, asthma and illness by discussing how these "attitudes" can be seen as social and moral actions.

Following this analysis of rhetoric and dilemmas in participants' talk, the same extracts are examined for how participant's management of blame and accountability situates their talk within an historical and moral context. These moral discourses are therefore discussed for how participants' versions of events are positioned within different

discourses and the connections that can be made to those moral discourses identified in the review of asthma literature in Chapter Two. This analysis will indicate the relationship between systemic discourse and individual utterance in talk about medicine taking. It will then discuss the potential for how individuals' talk may be seen as a manifestation of the moral issues that influence daily decisions about medicine taking.

#### *Chapter Five: Contextualising the Role of Moral Discourses in Talk about Prophylactic Medicine taking*

The analysis in Chapter Five will highlight specific interactional problems within the face-to-face interviews that needed to be overcome in order to make claims about the role of morality in talk about medicine taking. The talk identified in a minority of interviews could be seen to follow a different pattern to the talk identified in the body of the data. These "deviant cases" therefore required some explanation and a solution is presented drawing on ideas and techniques associated with Linguistic Ethnography.

This analysis will highlight the importance of understanding how participants' understood, or framed, the interaction taking place for the type of talk that was produced. It is argued that these framings are dependent on the interactional conditions of the interviews and other techniques from LE are drawn on to help specify the conditions of the interviews in this study. This analysis will indicate the circumstances under which speakers might have been preoccupied with accounting for their behaviour and when the role of morality may be present or absent in talk about medicine taking. Emphasising how the talk of participants was potentially restricted to the interactional conditions of the face-to-face interviews, raised the need to obtain "new" data that might validate the interview data. This was undertaken using a focus group, in which data was shared with participants and is the topic of analysis in Chapter Six.

#### *Chapter Six: Analysing Interactional Contexts in a Data-Sharing Focus Group*

This chapter discusses an exercise in providing a new piece of data in which moral discourses of medicine taking could be seen to be activated in the talk of participants. To provide what could be considered to be new data, a different type of interaction from the interview data was required which shifted attention away from individual's asthma management. A focus group was used to perform this task but rather than asking

participants further questions about their asthma management, data from the face-to-face interviews was shared with participants. The talk of focus group participants therefore provided a dataset which could be triangulated with the data obtained from face-to-face interviews and also with the moral discourses of asthma management identified in Chapter Two. It also provided a means by which participants could respond to findings from the interviews. Extracts from the focus group transcript are therefore examined for how moral discourses of medicine taking could be seen to be activated within the group's discussion. This analysis will therefore provide a more substantial basis for evaluating the importance of accounting for morality in discussions of prophylactic medicine taking.

### *Chapter Seven: Discussion.*

This chapter will review the rationale for this study and discuss what has been learnt about talk about medicine taking by using a discursive psychological approach to understand it. It will discuss the contribution of the different pieces of evidence about asthma medicine taking by considering the insights provided in how such talk is both interactionally constructed and also structured by wider moral discourses of illness management. Having built on the main analysis of interview data, through an analysis of the interactional conditions of the interviews and use of the focus group, the examination of properties of talk about medicine taking is extended beyond those examined in Chapter Four to incorporate lessons learnt about the production of talk in diverse contextual and interactional conditions, the allocation of blame and accountability within differing moral discourses and the relationship between structure and agency in participants' talk. Lessons learned from the analysis of data in this study will be used to assess how talk about medicine taking may now be better conceptualised, by offering an alternative to individualistic notions of attitudes and beliefs. This will facilitate insights into how researchers and healthcare professionals might be helped to better understand talk about asthma management specifically and perhaps chronic illnesses more generally. Suggestions will be made for how they may be more attuned to moral issues in talk and how treatment decisions may be made that are compatible with those issues. The author will also offer suggestions for further research, using the methodological approach taken in this study, within adherence research and also in research looking at how people manage chronic illness in everyday settings.

## *Chapter Eight: Conclusion*

This chapter will summarise what has been learned in this study of talk about prophylactic medicine taking for people with asthma and chronic illness generally, underlining the contribution of the thesis findings to existing knowledge on adherence to medications and the methodologies applied in this field. The chapter will conclude by re-emphasising suggestions for future research and also how healthcare professionals might more appropriately support people with chronic illnesses manage their conditions.

## **Chapter Two**

### **Morality in Talk about Prophylactic Asthma Medicine taking**

This Chapter is about building the rationale for studying the role of morality in talk about asthma management and prophylactic medicine taking. Approaches to medicine taking to date have tended to focus on people's beliefs and attitudes to asthma and medicines which have potentially missed important insights about how such talk is likely to orientate to cultural notions of appropriate illness management. Such a focus raises questions about accepting the meaning of this talk as accurately representing an internal cognitive state, such as an attitude. There is therefore a strong case for examining how talk about medicine taking is constructed within a discursive and social historical context. In Chapter One the interactional components in the production of morality in talk were examined. Chapter Two will now examine how asthma and morality have been historically situated and therefore the relevance of focusing specifically on notions of morality in talk about asthma medicine taking. This will be done by concentrating first on historical links between asthma and morality, and secondly by examining how morality is linked to the control of asthma symptoms in contemporary clinical asthma guidelines.

Initially, historical evidence will be offered that shows how asthma has been discussed in moral terms both in conceptualisation of its aetiology and in recommendations for prevention and treatment. This account will emphasise how individuals have been seen as accountable for the causes and solutions of asthma symptoms in various and shifting ways, manifesting in explanatory models focusing on individual psychology, personal habits, or individual exposure to environmental triggers. At the heart of these explanations lies the concept of control; of one's emotions, lifestyle or breathing and morality is evident in these explanations through the different evaluations that have been attached to different displays of control. A key point in the development of modern medical understandings of asthma is that although individuals are no longer seen as accountable and therefore in control for contracting asthma, morality has potentially shifted to how individuals control their symptoms. This shift in the focus of morality from cause to the management of asthma is mirrored in parallel shifts in conceptualisations of other chronic illnesses over the last hundred years.

After investigating the historical linguistic connections between asthma and morality, this chapter will go on to examine how morality is linked to asthma in British society today. Examining the specific medical conceptualisation of asthma management that informs current clinical practice offers insight into the broader moral framework that regulates treatment decisions in a clinical setting. Medicine is the dominant institution in the management of illness and disease. Whether through the NHS or in privately-provided services, medicine controls and distributes a vast array of resources to society in the management of health and illness. The people who need these resources are likely, (but will not necessarily), offer presentations of selves in ways which can enable them to gain access to required services and resources. It is therefore likely that in talking to other people about their health, they will manage such concerns within which control of oneself and one's asthma symptoms are likely to be a central focus. Theorising such regulation of talk by social discourse will then be addressed by re-interpreting findings from a research study that has reported clinician and patient talk about asthma management. This will involve tracing a path from the systemic discourses identified in medical discourses to their manifestation in individual utterances. However, tracing this path and other evidence will be drawn on to highlight how "self-control" is potentially one of many moral discourses that may influence how people talk about asthma management and make decisions about related prophylactic medicine taking. This will underpin a case to be made for broadening the analysis of morality beyond a medical lens to the management of illness in everyday life. Finally, having built a case for examining morality in asthma management talk, some conclusions will be drawn about what evidence is required for evaluating the importance of accounting for morality when interpreting talk about asthma prophylactic medicine taking.

### **Historical Links between Morality and Asthma**

For those tracing the history of asthma, the work of Moses Maimonides (1135–1204) and his "Treatise on Asthma" is repeatedly cited (Cosman, 1983; Diamant, Boot, & Virchow, 2007; Muntner, 1968; Opolski & Wilson, 2005; Rosner, 1981). His work may represent the earliest attempt to set out formal guidelines for the prevention and management of asthma and we can see how Maimonides constructed asthma self-management as a moral practice.

Maimonides was commissioned by the Sultan Saladin of Egypt to produce a series of dietary and behavioural recommendations for the management of the Sultan's son's acute asthma attacks suffered after having a cold. Maimonides' book sets out general principles of personal conduct relating to asthma, defined as "difficulty of breathing or a pain in the chest", and illness in general. Regulation of individual behaviour, in this case controlling one's diet, emotional state and habits, were seen as fundamental to health outcomes. According to Rosner:

Maimonides states that hygienic principles can be grouped into seven categories of which the first six are obligatory and the seventh is commendable: clean air, correct eating and drinking, regulation of one's emotions, exercise and rest, sleep and wakefulness, excretion or retention of wastes, and bathing and massaging. To these he adds the regulation of coitus as an important factor in a general health regimen. (Rosner, 1981, p. 247)

According to Cosman, Maimonides argued that "mental anguish, fear, excessive mourning, and stubborn agitation affect not only gait and appetite but also the respiratory organs, causing accumulation of noxious gases and preventing proper inhalation". To overcome psychic phenomena, Maimonides advised diet and medication allied with philosophy such as "laughing at death" and keeping the mind occupied with useful chores. However, Maimonides also argued that no medication should be prescribed for a condition curable by diet alone, "Medications encourage physiological dependencies, allowing the body's natural urges to become 'lazy', and ultimately to disappear because of lack of use." With some resonance with both Hippocrates' commitment to the patient and contemporary conceptualisations of patient-centred medicine, Maimonides' philosophy aimed to treat the "whole person" (Muntner, 1968). The central message of "The Treatise on Asthma" was that diet can be seen as a life pattern. A healthy body was necessary for a healthy soul. Medicine was seen to serve not only a physical but an ethical purpose, closely tied to philosophical responsibility - "*nihil ex nihilo*" ("nothing comes from nothing and nothing could be without effect").

The link between morality and the causes of asthma is less explicitly drawn in the Renaissance period from the 14<sup>th</sup> to 17<sup>th</sup> centuries, where the main focus on the causes of asthma was on environmental triggers (Cserháti, 2005; Ellul-Micalle, 1976).

However, Maimonides' indication that individual psychology played a part in causing asthma can still be seen at the heart of explanations of asthma 700 years later (Osler, 1892; H. H. Salter, 1860). William Osler, considered as a forefather of modern medicine, argued that "all writers agree that there is in the majority of cases of bronchial asthma a strong neurotic element" (Osler, 1892, p. 628).

In the early 20<sup>th</sup> Century the link between an individual's emotional disposition and asthma symptoms was increasingly replaced by explanations drawing on insight into the influence of the allergen. However, the role of individual psychology was rejuvenated in explaining the aetiology of a range of conditions in the 1930s to the 1950s. This largely reflected the emergence of the works of Freud and Jung and psychodynamic explanations of human psychology and behaviour. Over this period, psychodynamic theories were applied to a range of ailments, including asthma, by Alexander and colleagues at the Chicago Institute of Psychoanalysis and also by Dunbar based at the New York Psychoanalytic Institute. Both Alexander (1952) and Dunbar (1947) cited numerous individual patients' cases as evidence to support the connection between emotion and the symptoms of asthma. Clearly drawing on the theories of Freud (1940), explanations of asthma were constructed in terms of a relationship between individual physiology and unconscious trauma, whereby an emotional state brings about the physiological display of asthma symptoms. Early childhood trauma was regularly identified as a key to asthma in later life, as frustration of too little or too much motherly love, positioning asthma symptoms as a substitute for crying, or as suppressed sexual desire. Here the role of deterministic, unconscious, unresolved emotional conflicts were foregrounded for the perennial asthma sufferer. The individual's responsibility was not seen as orientated to external habits but to "seek help" to resolve internal causes.

In these psychoanalytical accounts of asthma, morality is seen as linked to the existence of asthma in two important ways. First, the quality and quantity of motherly love is clearly evident, with the mother being wholly responsible for providing the "right" kind of love. Second, it is clearly the morality of sexual desire that is central to the causes of asthma. Here, the mother is positioned as representing the regulator of social morality and is once again responsible for how this morality is communicated to her child. In both cases the child and person with asthma was therefore seen as holding unresolved frustrations relating to either maternal affection or sexual desire, both carrying



associated feelings of guilt and fears about expressing unconscious and shameful desires. Dunbar and Alexandar argued that, through some complex process, unresolved traumas led to their patient's asthma, seen as a manifestation of a self-perpetuating overdependence on one's mother, as a strategy for attention-seeking or as a response if rejected.

This theoretical link between individual psychology and physiology clearly constructed people with asthma as not only holding distasteful, immoral and unresolved desires, but also as devious manipulators. Whether these traits are seen as unconscious or not, the link between individual morality and asthma are clear and despite the increasing evidence that asthma was an organic, allergic condition, receiving a diagnosis of asthma would be clearly undesirable in this therapeutic context. In addition, as was typical of psychoanalysis, it was the individual's responsibility, with the analyst as "guide", to "confess" and come to terms with these conflicts (as interpreted by the analyst), in order to resolve one's symptoms. Again, morality can be seen to be elucidated through a display of individual control – of motherly love (both control of the child by the mother and of the mother by the child); of repressed sexual desire (both by inhibiting its expression and relinquishing control through psychoanalytic therapy); and through the manifestation of asthma symptoms, seen both as a loss of control and as a mechanism for gaining control (of a mother's affection).

### ***Morality and the role of metaphor in apportioning blame for illness***

The notion that the individual was responsible for both the causes and solution of one's asthma, theorised through a psychosomatic manifestation of symptoms, is evidenced in views of asthma widely-held well into the 20<sup>th</sup> Century, (Crocket, 1956; Knapp, Carr, Mushatt, & Nemetz, 1966). Similar connections have also been identified in numerous other conditions, demonstrating how such ideas have pervaded Western cultural understanding of illness aetiology and management. Susan Sontag in her passionate critique of the metaphorical language of cancer, tuberculosis and AIDS (1991), argues that the more an illness has numerous causes and indefinite origins, the more scope there is for drawing on metaphor to help frame it in terms of what is socially or morally wrong. Sontag argues, citing examples from fiction, poetry, texts from psychoanalysts, doctors and personal diaries, that morality has been applied through metaphor to explain

illness, and has for centuries, been related to individual psychology, again laying blame on the individual both for the causes and the resolution of illness.

Sontag identifies how in the 19<sup>th</sup> Century people were thought to get cancer through hyperactivity and hyperintensity and, as with asthma in Maimonides' recommendations, were advised to "bear the ills of life with equanimity" and not to "give way" (Sontag, 1991, p. 54) to grief. In contrast, and resonating with Dunbar and Alexander's theories on the causes of asthma, this connection between inhibited emotional expression and cancer has been reversed more recently with the idea that the symptoms of cancer are linked to repressed emotion (Sontag, 1991, pp. 23-24). This is also precisely how tuberculosis was frequently understood until the identification of the germ "bacillus". As seen with asthma, it is the control (or lack of) and (non)-display of emotions that is the cause of the physical symptoms of cancer, (or seen earlier with tuberculosis), and which provides the basis for how blame and accountability for one's illness is distributed. Despite the role of the unconscious in many explanations of illness in the first half of the 20<sup>th</sup> century, the effect of linking control of emotions with physical health is to equate individual freewill with good or bad health, as Sontag argues, by citing the psychoanalyst Groddeck (1977, p. 47) "The sick man creates his disease, he is the cause of the disease and we need seek none other".

Sontag argues that metaphor is used as a device to apportion blame and accountability for the existence of illness. The examples discussed here suggest that people with chronic illnesses, including people with asthma, may therefore also need to orientate to issues of individual control in the metaphors they in turn employ to provide the evidence to manage blame and accountability. For example, Sontag cites the journal of Katherine Mansfield a year before her death in 1923:

A bad day . . . horrible pains and so on, and weakness. I could do nothing. The weakness was not only physical. I *must heal my Self* before I will be well . . . This must be done alone and at once. It is at the root of my not getting better. My mind is not *controlled*. (p. 48)

Identifying how morality has been linked with asthma in ways similar to other illnesses emphasises that asthma is one of a range of illnesses which have been interpreted by the available cultural understandings in which their physical symptoms are manifested and expressed. These understandings are clearly not fixed and, importantly, underline that

asthma as a disease and its management can be seen to be as much a social phenomenon as an embodied personal experience, carrying important implications for how asthma is managed. This highlights difficulties in assuming that people are responding to a fixed object (“asthma”) when they talk about medicine taking, and also illustrates that decisions about medicine taking may be made in light of culturally available understandings of asthma, illness and medicines.

### ***Shifts in individual accountability: From causes to managing asthma***

Although it is possible to identify similarities with how the causes of cancer and tuberculosis have been conceptualised, asthma has typically not been regarded as shameful, morally-laden or as life-threatening as cancer or tuberculosis. Similarly, it is easier to identify more recently emerging illnesses which have been more heavily associated with moral connotations of causation and management such as AIDS (Sankar et al., 2002; Sontag, 1991) or chronic fatigue syndrome, (CFS/ME) (Horton-Salway, 2001). However, it wasn't until the 1960s and 1970s that the psychoanalytical links to asthma were widely disregarded and asthma was recognised as predominantly physical in its causes (although tackling the symptoms of asthma through different forms of psychotherapy can still be seen today), (M. Wentworth, personal communication, 2009). Whilst, psychology continued to make an important contribution to understanding asthma causation, theories linking the mind to the symptoms of asthma placed little importance on the dynamics of the unconscious, instead developing theories emphasising physiological responses to stress and emotion (Wright, Rodriguez, & Cohen, 1998), echoing 19<sup>th</sup> Century recommendations (as well as Maimonides) that asthma symptoms can be reduced by maintaining a calm emotional state.

The continuing connection made between psychology and asthma emphasises that whilst asthma is mainly considered to be a physical condition, it is a diagnosis applied to an array of symptoms also explained by an array of potential triggers, both physical and psychological. However, in contrast to some other non-terminal conditions whose aetiology is unclear, such as CFS/ME, (where people may often encounter difficulties in having their symptoms recognised and diagnosed as an organic condition), many people with asthma are commonly seen as resistant to a diagnosis, (Adams et al., 1997) often related to the intermittent nature of the disease (Halm et al., 2006; Horne & Weinman, 2002). The combination of an historical association of asthma with a fragile individual

psychology, explanatory vagueness regarding any one individual's diagnosis and the embodied experience of symptom-free periods help explain this resistance when framed within research contexts investigating beliefs about asthma. Importantly however, the movement in medical conceptualisations of asthma, from having psychosomatic to organic origins, may have shifted the patient's accountability away from the external causes of contracting asthma to personal accountability for the control and display of asthma symptoms. With medications being developed, which, for the first time began to effectively tackle the inflammatory symptoms of asthma and offer that control, it was now the individual's responsibility to use those medications as instructed. Health outcomes therefore, were increasingly seen as a result of conscious decision-making and research in the 1970s began to focus more directly on the individual knowledge which would ensure that those decisions were the "correct" ones (M. H. Becker, Radius, S.M., & Rosenstock, I.M., 1978).

### ***Asthma medications, asthma control and morality***

Although asthma medications had been developed since the early 1900s (Crompton, 2006), it wasn't until the 1960s that a treatment, salbutamol, which relieved symptoms without serious side-effects, was widely available (Diamant et al., 2007) and which is still the main form of asthma relief treatment prescribed today. Although forms of prophylaxis were in existence, medications largely oriented around the relief of asthma symptoms, bringing one's breathing back under control. A key shift in prescribing came about through an increased understanding that airway inflammation is a key feature of asthma. Coupled with a greater understanding that regular use of bronchodilator treatments potentially masks inflammation meant that, with the introduction of the first inhaled steroid prophylactic treatment in 1972, (Brown, Storey, & George, 1972; Clark, 1972), clinical practice shifted its conceptualisation of asthma care from "symptom control" to control by prevention through prophylactic treatments. However, it is only since the late 1980s and early 1990s that inhaled steroids have been widely prescribed. Explanations for this delay have been seen as public fears about inhalers following the UK asthma epidemic in the 1960s, combined with fears about steroids (Crompton, 2006; Kelloway, Wyatt, & Adlis, 1994; Price, 1994), or as a result of continued evidence of asthma as an inflammatory disease and resulting changes in asthma guidelines (Diamant et al., 2007; Stafford, Ma, Finkelstein, Haver, & Cockburn, 2003).

The delay in the wide dissemination of prophylactic medications indicates that the shift in the conceptualisation of asthma pathology and management, to one of inflammation that needed to be prevented, is relatively new. This raises the question about how well this way of understanding asthma is circulated in society beyond clinical and research settings. As Horne, Leventhal et al have found, many people with asthma continue to regard asthma as something that is not a continuous disease that needs to be under constant control. It is possible that when many people with asthma talk about how they view their condition and make decisions about medicine taking, they orientate their talk to the older “symptom control” framework of asthma management, in spite of fully understanding the need for prophylactic medications. This may be because a symptom control discourse is normalised within a wider range of social spaces and which may be more compatible with the everyday lives of people with asthma. Having looked at examples of how asthma has been linked with morality, realising that new forms of discourse may operate concurrently with older discourses raises questions about how discourses of illness management interact and transfer across discursive contexts to influence treatment decisions. In the following section more recent examples of text and talk are investigated to understand contemporary moral discourses of asthma management. This examination looks for evidence that the medical discourse of preventive asthma management carries notions of morality regarding asthma management that will be communicated through the use of clinical documents and will function to structure the talk and decision-making of clinicians and patients.

### **The Role of Morality in Contemporary Asthma Management**

The biggest influence on the practice of clinical asthma management today is the body of asthma guidelines. Asthma guidelines are based on what is considered to be the best available evidence and provide the main source of guidance for clinicians treating people with asthma in primary care in Britain. This evidence, largely generated through randomised controlled trials, seen as the gold-standard evidence informing guidelines, promotes the idea that the way to manage asthma is through the use of self-management plans and appropriate pharmacological treatment. Self-management plans (SMPs) incorporate advice about prophylactic medicine taking and adherence to both the plan and the medication is a key requirement for the plan to be effective. The review undertaken here will present key elements of policies that set out strategy and guidelines for managing asthma. It will then focus on asthma SMPs to build an argument for how

notions of morality can be seen to transfer from asthma management policies to clinical decisions and hence medicine taking. SMPs can be seen as “fixed texts” (Blommaert, 2005), potentially a powerful tool which may be transferred across contexts. In this instance the text of the SMP is “guided” by the recommendations within asthma guidelines within a clinical context which is then transferred to people’s everyday lives. To follow this process, the findings from a piece of qualitative research by Jones, Pill and Adams (2000) will be re-interpreted. Jones *et al* explored nurse, doctor and patient views of SMPs and reported general resistance to SMPs amongst these different participants. In addition, they reported a gulf between professionals’ concept of the “responsible asthma patient” and patients’ views. Instead of viewing the talk of participants reported in their findings as accurately representing individual attitudes, we can view this talk as a form of social action, enabling insight into how the clinicians and patients orientated to issues of blame, autonomy and accountability. This type of talk can be seen as an activation of an institutional moral discourse of asthma management apparent in asthma policy documents and which positions clinicians and patients as simultaneously empowered and accountable for their decisions. This will highlight how the individualistic ideology of patient-centred medicine creates a decision-making paradox for clinicians and patients when set against the evidence informing asthma guidelines.

### **Asthma Management Policies and Guidelines**

Two different sources were examined to identify evidence of a moral discourse of asthma management being constructed within current asthma policy. Although numerous guidelines have been developed over the last 30 years, the two most influential governing bodies influencing asthma management in clinical settings in the UK are the Global Initiative for Asthma (GINA) (2009) and the British Thoracic Society (BTS), (2008 revised June 2009). GINA, launched in 1993, is comprised of a network of asthma care experts, organisations and public health officials that collaborate to disseminate a global strategy for asthma management and prevention. GINA receives unrestricted educational grants from numerous pharmaceutical companies and works closely with the National Heart, Lung and Blood Institute and the World Health Organisation in the development of its strategy. The British Thoracic Society has worked in collaboration with the Scottish Intercollegiate Guidelines Network (SIGN) and who have jointly developed asthma guidelines since 1999. This decision to

collaborate was based on an agreed view that a new guideline was needed using “explicitly evidence-based methodology.” It was developed by a multidisciplinary group of practising clinicians who review the evidence using a standard methodology based on a systematic review of the evidence.

The language of the GINA report and BTS guidelines was examined for its discursive positioning of the roles and responsibilities of clinicians and patients. By choosing to review these documents, it is being proposed that one way in which medical representations and moralities of health behaviour are communicated through institutions is through the discursive power of bureaucracy and governance. This is not to exclude the possibility that moralities within medicine might come about and be disseminated in other ways but to argue that the institutional power of formal documentation is an important means for this. The focus here is therefore the study of the power of language in communicating the meaning of illness and how language and treatment decisions about illness are regulated, reproduced and produced through talk. These documents will be examined by drawing on the principles of language seen as social action discussed in Chapter One. On a literal level, this is self-evident in that asthma reports and guidelines are intended to “guide” clinical practice. However, guidelines may also be viewed as a form of rhetoric which construct doctors and patients in particular ways and links these constructions to specific types of behaviour. In particular, asthma guidelines work to “recommend” certain types of behaviour and not others, thereby indicating a moral value to these respective behaviours. The extracts selected here represent the rhetorical acts that the guidelines appear to perform. We can then examine these forms of rhetoric for the sort of moral discourse that appears to be constructed and subsequently whether we can see this discourse activated in talk about taking prophylactic medications.

## ***GINA***

In 2004, a key objective of the GINA guidelines was redefined. This was to develop a strategy for asthma management that was based on clinical asthma control rather than classification of the patient by asthma severity. The role of the health care professional was to: “establish each patient’s current level of treatment and control, then adjust treatment to gain and maintain control.” Asthma control is then defined as:

- No (twice or less/week) daytime symptoms
- No limitations of daily activities, including exercise
- No nocturnal symptoms or awakening because of asthma
- No (twice or less/week) need for reliever treatment
- Normal or near-normal lung function results
- No exacerbations

(Global Initiative for Asthma (GINA), 2009, p. xii)

GINA emphasises that any fall from this optimum state should result in re-assessment of asthma treatment, a warning of deteriorating asthma being an increased use of reliever medication. To achieve this control GINA sets out the appropriate medications that should be prescribed, “stepping up” and down asthma treatments as the required level of control is achieved. Stepping up may involve the introduction or increase in the use of prophylactic therapies, typically inhaled corticosteroids, but may also include leukotriene receptor antagonists, (an alternative tablet therapy) or long-acting beta-agonist treatments, which are usually prescribed in addition to inhaled corticosteroids.

The challenge to medicine is to ensure that control is achieved to help reduce “the burden of asthma.” This is viewed “not only in terms of health care cost but also of lost productivity and reduced participation in family life.” Preventive or prophylactic medications therefore have a critical role to play within GINA’s strategy and to succeed in their objectives it is essential that people with asthma take prophylactic medications as prescribed. GINA proposes that there are five interrelated components to their asthma management and prevention program:

1. Develop Patient/Doctor Partnership
2. Identify and Reduce Exposure to Risk Factors
3. Assess, Treat and Monitor Asthma
4. Manage Asthma Exacerbations
5. Special Considerations

(p. 50)

Component 1 has been a recent addition to the prevention programme and the doctor/patient partnership is seen as a process of relationship-building:



The partnership is formed and strengthened as patients and their health care professionals discuss and agree on the goals of treatment, develop a personalized, written self-management action plan including self-monitoring, and periodically review the patient's treatment and level of asthma control. Education remains a key element of all doctor-patient interactions. (p. xii)

It is also argued that clear communication between the health care professional and patient is the key to enhancing compliance. Key factors to facilitate communication are reported as:

- A congenial demeanour (friendliness, humor, and attentiveness)
- Engaging in interactive dialogue
- Giving encouragement and praise
- Empathy, reassurance, and prompt handling of any concerns
- Giving of appropriate (personalized) information
- Eliciting shared goals
- Feedback and review

(p. 51)

These factors are presented within a section which emphasises the importance of delivering effective education, seen as an integral part of consultations. In this section, the report also discusses barriers to adherence to prophylactic medications. Non-adherence is defined: "in a non-judgemental way as the failure of treatment to be taken as agreed upon by the patient and health care professional" (pp. 52-53). The following drug and non-drug factors are identified as related to non-adherence:

#### Drug factors

- Difficulties with inhaler devices
- Awkward regimes (e.g., four times daily or multiple drugs)
- Side effects
- Cost of medication
- Dislike of medication
- Distant pharmacies

### Non-drug factors

- Misunderstanding or lack of instruction
- Fears about side-effects
- Dissatisfaction with health care professionals
- Unexpressed/undiscussed fears or concerns
- Inappropriate expectations
- Poor supervision, training, or follow-up
- Anger about condition or its treatment
- Underestimation of severity
- Cultural issues
- Stigmatization
- Forgetfulness or complacency
- Attitudes towards ill health
- Religious issues

(p. 53)

The extracts presented here from the GINA report illustrate how the subjective experience of the patient is interwoven with the objective components required in achieving asthma control. We can see how these twin concerns manifest themselves within the context of patient education. Individual patient experience, feelings, beliefs and attitudes are recognised, but within the context of factors that may influence patient's adherence. The role of the clinician is to ascertain the level of asthma control and prescribe accordingly (the objective component), but also to act as educator to the patient, working to align patient attitudes and understanding with those required to adhere to the relevant medication. This is constructed as working in "partnership" which is "strengthened", principles which adhere closely to the concept of concordance held within patient-centred medicine initiatives (Pollock, 2005; Royal Pharmaceutical Society of Great Britain, 1997). However, with patient education positioned as central to the consultation, medical knowledge is upheld as the gold standard by which to measure the accuracy of beliefs and perceptions about health and illness. This tension between the knowledge of the patient and the knowledge of medicine is even more pronounced when specific guidelines and recommendations are set out for clinicians to follow within asthma consultations.

## ***BTS Guidelines***

At the outset, the BTS guidelines state that the guidelines are not intended to be construed or to serve as a standard of care and stress the important role played by the individual clinician and patient in making decisions about asthma management. However, as with GINA, the BTS state that the aim of asthma management is the control of the disease and sets out its definition of asthma control which closely matches the GINA definition. However, the BTS also state that “In clinical practice patients may have different goals and may wish to balance the aims of asthma management against the potential side effects or inconvenience of taking medication necessary to achieve perfect control” (p. 33). The BTS emphasise a “stepwise approach” for determining the most appropriate treatment to start with, stepping up or down the quantity and types of medication as is necessary according to the level of asthma control indicated by the patient’s symptoms. A key part of this assessment states that “Before initiating a new drug therapy practitioners should check compliance with existing therapies, inhaler technique and eliminate trigger factors” (p. 33).

The guideline consists of recommendations which are graded according to the amount and quality of the evidence available. Evidence is graded from 1++ being the highest quality down to 4. Randomised controlled trials (RCTs) or systematic reviews of RCTs are considered the gold standard evidence within this grading system. This is then followed by case control and cohort studies. At the bottom end of the grading are “non-analytic studies, e.g. case reports, case series’ and expert opinion”. The “Grades of Recommendation” A, B, C and D are assigned based on the levels of evidence that are available for each area of asthma management. A tick box is also used to indicate “recommended best practice based on the clinical experience of the guideline development group.” We can see this grading method played out in the stepwise recommendations where each of the 5 asthma steps, from mild asthma at step 1 to severe asthma at step 4 and 5, recommend a medication and state clearly the grading which that recommendation is based upon. The recommendation for the use of regular preventive therapy has an “A” grade, meaning it has a range of high-quality evidence available to support that recommendation (p. 36). This recommendation provides clear guidance for the practising health care professional which can be broadly applied to all

asthma patients. BTS also set out the asthma-related features which indicate that a patient is likely to benefit from an inhaled steroid.

- Exacerbations of asthma in the last two years
- Using inhaled  $\beta_2$  agonists three times a week or more
- Symptomatic three times a week or more
- Waking one night a week

(p. 36)

*The asthma review and self-management plans/action plans:*

According to the BTS guidelines, finding the optimum treatment for the patient's level of asthma severity involves regular review to enable "stepping down" of treatments.

Regular review of patients as treatment is stepped down is important. When deciding which drug to step down first and at what rate, the severity of asthma, the side effects of the treatment, time on current dose, the beneficial effect achieved, and the patient's preference should all be taken into account. (p. 46)

A key proposal within the guidelines is that a central part of any asthma review is for the use of self-management (SMPs, also known as action plans) (see pages 107-108 of BTS guidelines for example plan). It also recommends that the number of patients receiving SMPs should be audited. It also suggests that audits that feed back the guidelines' recommendations to clinicians, regarding the management of individual patients, may improve outcomes.

Proactive clinical review of people with asthma improves clinical outcomes. Evidence for benefit is strongest when reviews include discussion and use of a written action plan. (p. 80)

The ideal content of an asthma review consultation is uncertain. Discussion and provision of a written action plan leads to improved outcomes. Other activities likely to be important are reviewing understanding of medication role and use, checking inhaler technique, recording lung function. Structured review systems

such as... improve the recording of relevant data and may prompt a search for causes of suboptimal asthma control, such as under-treatment, poor adherence or poor inhaler technique. However, such tools can lead to a more physician-centred or template-directed consultation. Reviewing patients using a patient-centred style of consultation can lead to improved outcomes. (p. 81)

This emphasis on a “patient-centred style of consultation” is evident throughout the BTS guidelines. There are lots of reference to the perspective of the patient and emphasis of the individual and personalised nature of asthma management, “personalised action plans”, “patient-centred style of consultation”, “ownership”, “patients may have different goals”, “patient preference”. In addition the “ultimate judgement” of the clinician is essential.

As was seen in the GINA report, the role of education, offered by the clinician, is nevertheless fundamental in this approach as we can see in the extracts below.

Successful [self-management] programmes vary considerably, but encompass: Structured education, reinforced with written personal action plans, though the duration, intensity and format for delivery may vary.  
*Recommendation:* Introduce personalised action plans as part of a structured educational discussion. (p. 85)

Checklist 1. Suggested content for an educational programme/discussion.

This checklist is intended as an example, which health professionals should adapt to meet the needs of individual patients and/or carers. **The purpose of education is to empower patients and/or carers to undertake self management more appropriately and effectively (*my emphasis*)**. Information given should be tailored to individual patient’s social, emotional and disease status, and age. Different approaches are needed for different ages. (p. 86)

Here, (and also within the GINA report), we can see how the provision of information and an SMP is equated with the individual patient as empowered decision-maker. This positioning of the clinician and patient as informed decision-makers means that responsibility for treatment decisions is considered to lie with the doctor, nurse and patient. However, the graded “evidence” means that if clinicians do decide to reject the

recommended treatment option they are going against the “best practice” set out within the guidelines. This position is reinforced at different points within the document and the advice is clear that patient and clinician choice needs to take place within the structure of the guidelines.

Self management programmes will only achieve better health outcomes if the prescribed asthma treatment is appropriate and within guideline recommendations. There is some evidence that ownership of a self management plan may attract better treatment (i.e. increased steroid provision from attending physicians). (p. 86)

*Recommendation:* Initiatives which encourage regular, structured review explicitly incorporating self-management education should be used to increase ownership of personalised action plans. (p. 88)

The BTS guidelines offer little insight into how to overcome situations where the goals of patients do not easily match the advice in the guidelines, other than to ask open questions, as set out in a section titled “Compliance and Concordance” (p. 86). It is arguable that the space for treatment options is therefore limited within the structure of the asthma guidelines. This potentially creates a situation whereby patients, doctors and nurses are held accountable for problems arising in the management of a patient’s asthma as we can see in the below extract taken from the opening paragraphs of the BTS guidelines.

The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient’s case notes at the time the relevant decision is taken. (p. 1)

This discursive framework of the doctor-patient relationship as “concordant”, “proactive” and “empowered”, set against the need to document “significant departures”

from the guidelines arguably creates a decision-making paradox whereby patients, doctors and nurses are simultaneously responsible or “empowered”, yet restricted by the treatments available and regulated in their decisions. As a result, poor health outcomes, or the “burden” of asthma, is potentially positioned a result of treatment decisions being outside of “best practice”, lacking “concordance” with patient’s perspectives, or clinicians not being “proactive” enough.

### **The Manifestation of Accountability in Talk about Asthma Management**

The positioning of clinicians and patients, within asthma guidelines, as both accountable and empowered can be seen to be manifested in interviews with clinicians and patients regarding SMPs. In a qualitative study using focus groups, Jones, Pill and Adams (2000) explored the views of health professionals and patients with mild to moderate asthma on the role of guided SMPs for asthma. Jones *et al* found that in the majority of cases, SMPs were received unenthusiastically and neither patients nor clinicians considered them to be either useful or effective in managing asthma. This resistance to SMPs may indicate the underlying tensions manifest within asthma guidelines between the evidence-based recommendations and the notion that doctors, nurses and patients have autonomy and are responsible for the decisions that are made about treatment. We can briefly re-examine some of the extracts that Jones *et al* provide to theorise that this tension might be transmitted from the proposal to use SMPs stated within asthma guidelines to the talk of doctors, nurses and patients in their discussion about the role of SMPs in asthma management. This might then be used to theorise more generally regarding the provision of asthma interventions and the everyday lives of people with asthma.

In primary care, specialist respiratory nurses are commonly responsible for managing patients’ on-going asthma through asthma reviews, whilst the GP tends to see asthma patients for emergencies. The review of the work of Jones *et al* reported here, therefore focuses on the views of nurses rather than GPs as this is likely to most effectively demonstrate a case where the prevalence of accountability in talk about SMPs can be seen. Their study offered vignettes of patients talking about SMPs to elicit participant’s views in focus group discussions. The following extract was provided by Adams *et al* as representing the main issues to emerge from focus group discussions with nurses.

Nurse W: They do have a place but you have to give them to motivated patients—with instructions there to make sure they will seek medical advice if the condition is deteriorating . . . And not give it to people who would take it too far and leave it too long before seeking help.

Nurse X: Well they say, “The nurse has given me this so I should be able to manage myself.” Your concern is then whether they will try to manage too long before coming back, and then they reach a crisis.

Nurse Y: You can't cover every eventuality on a plan either—you can't account for every symptom so some of them would say, “Well, I haven't got that or the peak flow hasn't quite got to that stage so I'd better wait until it gets there.”

Moderator: You're making them sound quite dangerous.

Nurse X: They can be, especially for very intelligent people—they are the worst. (Jones et al., 2000, p. 1508)

These researchers report that some nurses considered patients as “overconfident” or “cocky” and that their own guided SMPs could lead to “bad habits” which could militate against optimal health and treatment. Nurses (and GPs) also reported that the clinician-patient perspective was regarded as fundamental in ensuring effective asthma management and were concerned about patients “blind obedience” to standardised plans, particularly with patients who lacked “intelligence”, “commonsense” or didn't understand the SMP. The clinician is therefore the key in educating patients, who, along with SMPs, are accountable for asthma management problems.

In the examples provided by Jones *et al*, patients were seen as “not the best judges of their own health” and were constructed into diverse groups: motivated-unmotivated; intelligent-unintelligent; cocky and overconfident; self-doubting and lacking confidence. Different asthma management behaviours are associated alongside these identities. “Motivated” patients follow instructions and seek help when needed, unmotivated “leave it too long”. “Intelligent” patients think about their asthma and the SMP too much and make incorrect decisions about their asthma and again avoid seeking medical advice. “Cocky and overconfident” patients are also associated with a reluctance to seek medical advice when needed. These statements serve the purpose of managing any potential accusations that the nurse is incompetent or has not effectively communicated the correct piece of education about their patient's asthma. Whether this is true is not the issue here. Instead, the focus is that nurses can be seen to be managing



their accountability for their patients' asthma, and their expertise as nurses in discussions about SMPs. By constructing SMPs as potentially rigid and patients as having difficult personalities, they achieved two things. First, crises in patients' asthma are blamed on SMPs and patients, and not nurses. Second, the role of the nurse is the most important in achieving positive outcomes positing that if patients attended the surgery when they needed to then there would be fewer problems. They are therefore managing the potential threat to their expertise as nurses, that SMPs potentially undermine the need to have a nurse at all. The moderator neatly summarises what has been achieved in the talk about SMPs in this focus group when they say "You're making them sound quite dangerous."

The management of accountability and expertise in the nurses' talk highlights a moral dimension for their clinical practice and hints at tension between the dictates of medicine within asthma guidelines and clinical opinion. By dealing with potential issues of blame for patients' poor asthma management, the talk of these clinicians can be seen as versions of the moral discourse of asthma management evident in the asthma guidelines. In the guidelines, it is the clinician who is simultaneously autonomous and independent, (in concordance with the patient) and accountable for treatment decisions. From the limited data available in the reported views, the nurses appeared to be reproducing a version of this discourse, produced interactionally within the focus group of the study reported by Jones *et al.* This is evidenced in how nurses appeared to be managing an interactional tension between professional autonomy and accountability, argued as creating a "decision-making paradox" for clinicians. They did this by constructing a contingent relationship between the level of the patient's asthma control and the clinician's accountability. The nurses' constructions of SMPs as potentially standardising patient's asthma management, patients as "not the best judges of their own health" using various categories of patient, alongside a concept of time ("leave it too long"), are critical rhetorical devices in building this relationship. The moral discourse of asthma management can be seen to structure the nurses' talk but at the same time a newer, more complex version of this discourse is created within the focus group interaction. Understanding how SMPs, patients and time are constructed and deployed as devices within this talk, links the individual utterances of the nurses to the systemic discourse of asthma management suggesting that such a discourse is transferred across contexts through the fixed text of the guidelines.

We can now briefly examine the patient views in the paper by Jones et al for evidence that issues of accountability and autonomy were also managed in their discussions of asthma management.

Jones et al reported that:

“All but one of the patients agreed that self-management plans might be of use to other patients but, for differing reasons, were not relevant for them.”

“Non-compliant patients felt plans could be useful for people with “more serious” or “proper” asthma, whereas compliant patients felt they were “pointless for them personally” or “they already had a full understanding of the issues.” (Jones et al., 2000, p. 1509)

Although there is limited data to interpret the talk of patients reported in the study by Adams et al, there is a strong indication that the patients within the focus group “minimised” and “normalised” their asthma. This was evident in how participants positioned their own asthma with those with “proper” or “more serious” asthma. This sort of talk which minimises illness has been identified across a range of conditions and levels of severity (Bury, 2001; Coxhead & Rhodes, 2006; Protudjer, Kozyrskyj, Becker, & Marchessault, 2009; Prout et al., 1999). It has been argued that this type of rhetoric is common because people with chronic illness need to present themselves as fit to participate in society (Frank, 1995; Williams, 1993), to restore former selves (Charmaz, 1990; Yoshida, 1993) or as someone with a “health problem that is not an illness” (Cornwell, 1984). Despite the limited available data, it can be argued that the idea of using SMPs, for patients in the study by Jones *et al*, potentially placed them and their asthma outside of these categorisations and may have been seen as threatening the discursive positions that they constructed in their talk. “Why do I want something written down? You know . . . your chest tells you” (p. 1509). The version of asthma that the person constructed was therefore critical in undermining the potential view that they needed to be taking their asthma more seriously; that they should have been using an SMP in their everyday life; and should be held accountable for adhering to the instructions set out in the SMP.

As with the nurse’s views, we can see how patients attempted to provide an autonomous and authoritative version of their asthma which functioned to resist the use of SMPs, as well as indicating how they were responsibly managing their condition, “we are self

managing to a certain extent, where they give us the medication to take—so we are self managing ourselves, aren't we” (p.1509). However, the patients’ discursive positions regarding SMPs and their own asthma hinted at worlds where minimising their illness might be appropriate. For these people, with mild to moderate asthma, managing their condition potentially needed to be done in a way which did not place the person beyond the realms of what is considered normal for the activities that they engage in everyday life. This indicates a moral agenda in the patient’s everyday lives about what constituted normal and acceptable behaviour within the different social networks that they participated in. It may be argued that these concerns were hinted at in their talk because of the need to resist the challenge to these notions of normality that meanings of asthma and SMPs represented. Their minimisation of asthma can be seen as an attempt to resist alternative perspectives that view their asthma as “more serious” or a “proper” disease that needs close monitoring. It would be likely that people, considered to have mild to moderate asthma, in dealing with healthcare professionals and researchers, may construct a version of their asthma that orientates to these everyday concerns when discussing their use of prophylactic medications. These may be managed in conjunction with ideas about responsible illness management as seen from a medical perspective.

There is therefore a conceptual need to engage with these alternative moral perspectives of everyday life and how they do or do not interact with medical perspectives on illness management. More fully appreciating how different moralities may operate in asthma management talk may help understand the limitations of the current clinical discursive context that positions clinicians and patients as responsible within a restricted range of choices. We might also be able to understand how cultural explanations of illness management influence the decisions that people make about medicine taking and illness prevention in everyday life.

### **The Role of Lifeworld Discourses of Illness Management and Medicine Taking**

The moral discourses of illness management which may have most influence on everyday decisions about medicine taking are those discourses which circulate social settings, such as work, home, school, where the individuals concerned have an interest at stake. The importance of locating the accounts that people provide within a cultural framework has already been illustrated in studies of talk of people with other chronic illnesses (Bury, 2001; Lawton, Ahmad, Peel, & Hallowell, 2007; Williams, 1993) and

in studies of health and illness perspectives more generally (Backett, 1992; Cornwell, 1984; Crawford, 1984). In asthma, “minimisation talk” such as that identified in the research of Jones et al research, potentially provides one example of the value of engaging in the symbolic space of people with asthma outside of medicine’s illness management discourse. This symbolic space of everyday life can be referred to as the “lifeworld”. Originally a concept coined by Schutz (1962) as “natural attitude”, it is used in this research to refer to the “symbolic space in which our personality and culture are experienced” (C. I. Salter, 2005).

In this study, the objective was to identify evidence that moral discourses, from medical and lifeworld origins, were activated in talk about prophylactic medicine taking which then indicated some of the grounds upon which decisions about medicine taking were made. Lifeworld discourses were therefore theorised as alternatives to institutional medical discourses of asthma and illness management that have been discussed in the analysis of asthma guidelines. For example, Adams, Pill and Jones (1997), in a study of different asthma identities, highlighted how participants varied in the people and contexts in which asthma was revealed. Respondents’ talk was interpreted as “identity work” drawing direct links between respondents’ “attitudes to medication” and “beliefs about their condition.” Whilst this study adopted an alternative perspective in how such talk is conceptualised, the realisation that illness talk, illness identity and illness management differs across social contexts reveals the differing moral dimensions that circulate these social networks and lifeworld contexts.

### *Self-control and other lifeworld discourses*

Individual culpability, for the causes and display of asthma and other chronic illnesses, has been shown in this chapter as linked, circulated and shifted in a variety of linguistic contexts through history. Sontag’s (1991) analysis of illness metaphors highlighted how the need for self-control has been evident in culturally common, or “lay” conceptualisations, as well as authoritative theories of illness aetiology and symptom prevention. Gareth Williams also identifies lifeworld concerns with self-control, in his analysis of the role of morality in interview transcripts with people living with rheumatoid arthritis (Williams, 1993). His analysis demonstrated that the moral life of the lifeworld has a powerful influence on decisions made about health and illness, to which medicine taking is only part. He discusses how (p. 102) society values “self-

control” and the tension this has with living with a chronic illness because it involves a loss of control through interference on daily activities. Williams’ analysis reconstitutes behaviour surrounding chronic illness management as less about denial or acceptance within a rehabilitation framework but, rather, what he calls “moral practices”, that are a continued expression of the self in a moral context through mundane activities.

Williams also argues that terms such as “adaptation”, “adjustment”, “coping”, when applied to how people live with chronic illness, are based on a world of contingency. These are categorisations of actions according to potential adverse outcomes, and in the case of asthma, this is an asthma attack, (this type of talk was evident in the nurse vignettes discussed in the research by Jones et al). Williams argues that these categorisations fail to account for peoples’ talk about their illness not orientating to these contingencies. People with chronic illness, he argues, are not trying to display an optimum management strategy but how they wish to be understood according to the differing moral dimensions that inform their lives.

Self-control has been made even more explicit in asthma management literature where control of one’s breathing has been regarded as a display of emotional or symptom control. Self-control in asthma management is therefore set within an institutional and lifeworld context and is potentially an important discourse which circulates these different cultural spaces. A moral life set within a lifeworld context where self-control is paramount, may mean a life where medications have limited functions and are hence used selectively. Interpreting people’s talk about chronic illness and medicine taking as “attitudes”, lacking a consideration of moral and interactional context, runs the risk of inappropriately judging that person outside of that moral context and according to a different set of criteria. Such “attitudes” are often subsequently used as evidence that the attitude needs to be changed if the health-related behaviour is to change. Seen in this light, educational strategies are only likely to work if they can be accommodated into this moral framework.

However, talk about health and illness may not be restricted to notions of self-control and the embodied display of symptoms, but may also orientate to other lifeworld discourses that impact upon discussions of health and illness (Cornwell, 1984; Pajari, Jallinoja, & Absetz, 2006). For example, Cornwell’s study of East Londoner’s accounts of health and illness demonstrated a range of lifeworld concepts and discourses that

speakers connected between work and health including: good and bad people, malingerers, hypochondriacs, stoics, hard-working, lazy, moaners and cheerful people. These insights showed that in discussing one's health it may not be sufficient to only present oneself as fit for work but it is also necessary to display a set of personality characteristics that go along with "being healthy." This point emphasises that health-related discourses do not have clear boundaries that speakers orientate to independently. Cornwell's data highlighted how lifeworld concepts, that circulate lifeworld settings regarding work, interact with one another but also with medical discourses. In discussing health and illness management therefore, speakers can be seen to manage multiple concerns simultaneously. Decisions about medicine taking may be informed by the moralities of differing social networks in which people live their lives and competing moralities may create difficulties for the rhetorical work the participants undertake.

Insights of talk within lifeworld contexts offer a distinctly different understanding of medicine taking talk, than that offered by social cognitive conceptualisations. Rather than viewing statements about medicine taking as orienting to one object of thought, such as asthma or medicine taking, a lifeworld view raises the possibility that multiple concerns are attended to simultaneously. Some of these concerns are likely to be based on the circulation of moral discourses of illness management and others regarding acceptable personality characteristics and behaviour in the social settings which speakers have a stake in. In addition, understanding talk about health and illness as about speakers attending to multiple perspectives within differing social spaces and social networks, positions medicine taking as an activity that needs to be compatible with participation in everyday life and extends the experience of asthma from a physical to social experience.

### **Evidence Required to Investigate the Discursive Construction and Role of Morality in Talk about Prophylactic Medicine Taking**

Chapters One and Two have thus far presented a rationale for exploring how people construct prophylactic medicine taking within interactions and link these constructions with notions of morality. This argued that our understanding of talk about asthma management and medicine taking needs to be reconstructed and re-specified, to move from a view of talk as representing individual attitudes to one which sees talk as

language constructed within social spaces. This re-specification emphasised that it is only when we view such talk from within a discursive framework that we can fully understand speaker's orientations to moral issues in their talk. It is now important at this stage to establish what is meant by morality in this study and the evidence that is required to investigate this definition of morality in talk about prophylactic medicine taking.

### *Definition of morality*

By situating the role of morality within an historical and interactional context the author of this study constructed a version of morality itself. This is a concept that is not fixed or real but one that varies both between and within interactions about illness management and medicine taking. Members of interactions may mutually construct these versions drawing on culturally-available and shared understandings about appropriate illness management and behaviour. In this chapter a "moral discourse of asthma management" was discussed within asthma prevention initiatives and clinical practice that carries with it notions of good and bad patients, correct or incorrect beliefs and therefore a code of conduct about appropriate behaviour regarding asthma prevention and management. However, people may also orientate their talk to social aspects of life in any number of ways, such as a code of conduct within the workplace or a morality of motherhood. Moral discourses of illness management are therefore likely to be used in flexible ways by different people in different circumstances at different times and used functionally to position the person within those particular moral frameworks. The connections that speakers make between morality and illness are therefore related to the social networks which reproduce those moralities. The "communicative ecology" (Gumperz, 1999, pp. 453-471) of our lifeworlds determines the sorts of moralities that are reproduced and produced in our interaction with other people. They are therefore likely to be multiple, can be seen to be managed simultaneously (Radley & Billig, 1996) and conceivable that moralities may be contradictory.

### *Identifying evidence in a discursive analysis of talk*

The aim of this study is to evaluate the importance of understanding how medicine taking is discursively constructed within interactions and how moral discourses of

medicine taking can be seen to structure this talk. We therefore have to ask what counts as adequate evidence that interactional issues and discourses of morality will influence such talk in a variety of social contexts. The answer to this question will vary depending on the assumptions that the analyst brings to the data: how talk is understood (its ontological assumptions); and the knowledge that it produces (its epistemological assumptions). One way to clarify the differences between the view of evidence taken in this study from the previous work examining talk about medicine taking is to apply some different ontologies and epistemologies to a single sequence of interaction, as it is how different paradigms of knowledge treat these cases which reveal their differences most effectively. The study by Adams, Pill and Jones (1997) on medication, asthma and identity argued that people, in living with chronic illness, actively constructed their identity in one of three ways: as accepters, deniers or as pragmatists. They adopted Mead's symbolic interactionism (1934) to emphasise a dialectical relationship in respondents' "asthma identity work" between personal identity, the "I", and social identity, the "Me". The following extract is taken from a respondent categorised in their study as an "accepter."

I know that some people have funny ideas about asthma. Think you're weak...disabled almost. Mind, I never have that sort of attitude from people. I think it depends on what sort of person you are. I don't act ill or weak or anything so people don't think of me that way. I work all hours and keep the house going.

(Woman, aged 32, shop worker, Adams, Pill & Jones, 1997)

From a symbolic interactionist perspective it may be argued this particular person drew on an "organised set of attitudes of others" (Mead, 1934, p.26) regarding "asthma as a disability", to construct her own self-image as someone who "don't act ill or weak". When viewed from within this framework, identity, attitudes and beliefs are viewed as an aggregation of interactions and in this sense are seen as a series of discrete encounters. The extract by Adams et al extract is therefore treated as unique to that interaction as are the set of beliefs, attitudes and identities the person holds. When viewing this extract from within a positivist framework, which has been the dominant paradigm in explanations of medicine taking and adherence, this person's talk is also likely to be seen as unique to this individual and is certainly not sufficient to



demonstrate that people with asthma more generally, or even just those who can be classified as “non-adherent”, engage with a moral agenda in their talk.

Rather than viewing the talk within this extract as unique to the individual or as a relationship between the generalised attitudes and identity, this study was interested in how notions such as “asthma as a disability” are circulated through society and drawn on by individuals within interactions to address particular moral agendas that were activated within those interactions. From this view the speaker in the extract by Adams et al was not just reporting her self-image, she was doing so in a cultural framework which assigns a positive moral connection between illness and work. Viewed in this way, her talk can be seen to be a product of discourses which are commonly shared but manifested in novel ways to meet particular interactional demands. The anthropologist Birdwhistell (Varenne & McDermott, 1998) provided a particularly illuminating analogy to describe such connectivity in language. Individuals in a social context can be viewed as threads on a rope which, on their own, are discrete, discontinuous objects but when made into a rope become impossible to delimit within the twisted continuity of the rope. Within an individual sequence of talk, the analyst is not just looking at an individual account or thread that is discrete and separate from other individuals. Rather, the language that is produced at different points is seen as inseparable from the language produced by other individuals (threads) in other interactions because both are a product of and productive of wider historical discourses—the rope—in which talk about health, illness, and medicine taking can be seen. This is not the same as saying that all threads or individuals are the same, but rather to say that the language in one account is connected with the language used in another through social contexts that are shared and that can be seen to be manifested in talk. When seen within this view, assigning individuals into different categories is a choice of our level of analysis and an artefact of traditional social scientific practice.

From the discursive perspective taken in this study, it made no logical sense to demarcate the analysis as related to separated individuals; instead the author looked for sequences of interaction which were the different threads through which to trace a path from a broader discourse of morality on asthma medicine taking to the individual. The methodology required (and set out in the next chapter) would therefore provide the tools to identify some of these different threads. By doing so, we can see some of the ways in

which different social discourses of morality, as different parts of the rope, may be momentarily manifested within interactions.

### *Types of evidence required for a study of interactional issues and moral discourses*

Having established what was counted as evidence within this study of talk about medicine taking, the different types of evidence that were required can now be set out. This chapter has reviewed literature that identified evidence that discourses of asthma causation and management have historically been intimately connected with notions of the virtuous or irresponsible patient. The discursive concept of “control” (asthma and emotional) could be seen to lie at the heart of these discourses and which allocate responsibility and accountability for the causes and more recently the management of asthma and chronic illness management more generally. There was also evidence that suggests that notions of self-control as well as alternative notions of appropriate illness management circulate the lifeworlds in which people live with conditions on a daily basis. The evidence that is required in this study is to make these connections with the talk of the participants and there are three types of evidence that are presented here as necessary to make these links.

First, there was a need to identify evidence of talk about medicine taking that could be seen to have a moral agenda. That is, talk that could be seen not simply as accurately articulating an internal cognitive state such as an attitude or a belief but evidence that demonstrated the speaker’s talk as serving a particular function to which the speaker could be seen to be orienting towards. This goes beyond simply reporting one’s views but identifying evidence that shows the speaker working to present themselves, their behaviour and versions of events in particular ways, whilst at the same time undermining any potential threats to this construction of “facts.” It is the specification of this evidence that is necessary here which will allow us to shift our conceptualisation of this talk to one which views it as language constructed within a social space and which will illustrate that the interactional context is vital for understanding this type of talk.

The second type of data that was used and which is intimately connected to the first is evidence that moral, culturally-available explanations of asthma, illness management and medicine taking were activated within interactions and structured the talk within

those interactions. Identifying evidence of participants engaging with moral discourses is evidence that they are not simply reporting attitudes but that their talk is structured by culturally-shared understandings of illness management. This enables us to make assertions about the circulation of different moral discourses to different social spaces which play a role in what is said about illness management and medicine taking. Instances of interactional sequences in which participant's talk can be traced to the discursive connections between morality and medicine taking identified in published literature such as the asthma guidelines, situates that talk within a social structure. This is achieved by identifying talk that orientates to issues of blame and accountability that positions the speaker within these explanations of illness management. It also allows the possibility for insight into alternative moral discourses of illness management and medicine taking. These may be discourses that may be circulated in the social networks, the lifeworld of participants and which may be particularly pertinent to the decisions that the participant makes about taking medications.

Third, it was necessary to identify evidence that allowed the author to make some generalising statements about the interactional circumstances in which moral discursive constructions of prophylactic medicine taking are likely to be reproduced. This is an exercise in identifying links from talk identified in one interactional space to a different interactional space. The need for this evidence was emergent in this study through a realisation that some participants did not justify their medicine taking. It was therefore necessary to contextualise the talk of study participants to identify boundaries to moral talk of medicine taking and to provide evidence that enabled the author to assess the limits of extending these interpretations of talk beyond that of this study's participants. This was achieved in two ways: firstly by comparing and contrasting sequences of interaction where participants could and could not be seen to be justifying their medicine taking and secondly by identifying moral discourses of medicine taking in the talk of participants in a different interactional space. The analysis of deviant cases in Chapter Five will demonstrate that obtaining this sort of evidence required the view of context to be broadened outside of linguistic manifestations of discourse to incorporate more ethnographic, non-textual forms of context that might have influenced what participants said within interactions. This is because what people say about medicine taking may be dependent on having access to resources that are not overtly apparent in a purely textual analysis.

The knowledge developed from this work will then be applied in Chapter Six in a data-sharing focus group. These data, in this research setting, were constructed with both linguistic and ethnographic features of context in mind. The choice and implementation of this method was based on the rationale that if participants could be seen to be justifying their asthma management and medicine taking in a different interactional context then this provides a new piece of evidence in which the influence of moral discourses of illness management and medicine taking can be seen.

### **Summary**

The solution to asthma management problems as offered through the GINA initiatives and the BTS guidelines is to educate the patient so they are “empowered” to manage their asthma more effectively. This implicitly assumes that medical interventions become more acceptable through the acquisition of knowledge and Jones et al showed this relationship as also constructed within the clinician’s accounts. It has been argued here that the result of this simple relationship between individual knowledge and individual choice is the construction of notions of responsibility within talk about chronic illness management (Crawford, 1984; Lupton, 1995) which focus at an individual level. This involves a discourse about who is responsible for treatment decisions, what a “responsible patient” means, what actions are “responsible actions” to control asthma by patients and clinicians, and who is responsible for the experiences that patients have with their asthma, whether as well-controlled or in the event of an asthma crisis.

The review of asthma in this chapter was developed by selectively identifying literature to formulate a theoretical link between how asthma has been conceptualised and notions of morality. It presented the case that it may be fruitful to investigate how moral discourses of asthma management influence talk and decisions about medicine taking. However, it is important to be cautious about being over-deterministic in extrapolating to what happens when people with asthma talk about medicine taking across a range of social situations. People live with chronic illness and asthma in a variety of social contexts and interactions. The notion that people with asthma need to display different forms of embodied control has its origins in an analysis of the institutions which have had the greatest influence on the production of the knowledge about asthma and its management. It may be that only in certain types of clinical encounters that these types

of concerns are activated in talk. Although clinical encounters play a vital role in decisions about appropriate treatment and follow-up with patients, they are only part of a social world in which people live with asthma. There may be many other notions of morality that have been linked with illness and asthma management that have not been documented or have been of interest to researchers. This point is highlighted by Frank in drawing on Tim Brookes' reflections on his life with asthma: as becoming someone who is "successfully ill". This moral success is not confined to how he is perceived within clinical encounters but is about being "more than compliant: his 'healing' means learning to live with asthma creatively and meaningfully and he knows he can only learn this not as a patient but by going outside the clinic" (Frank, 1997, p. 136).

Identifying the interactional and moral in talk about medicine taking entails active discovery and investigating such talk will help make visible how notions of morality operate so as to structure and be constructed within dynamic interactional spaces. It is argued that such an investigation can provide a richer understanding of this talk than that provided by individualistic notions of attitude or belief. It is this understanding that may then provide clues to a fuller appreciation of the medicine taking decisions made by people with asthma, and other chronic illnesses in everyday life.

## Chapter Three

### **Methodology and methods for investigating the discursive construction and role of morality in talk about prophylactic medicine taking**

In Chapters One and Two it was argued that attitudinal approaches to adherence risk overlooking important insights about how attitudes to health and illness, beliefs about medications are situated within institutional, historical and interactional contexts. Examples of talk about health and illness were shown to be situated within these contexts, manifesting in notions of morality being oriented to by speakers. The research approach being developed here identifies problems for traditional attitudinal approaches to adherence, as it suggests that talk about medicine taking for people with chronic illnesses is also likely to be set within a moral framework and therefore will not simply represent some internal state. Chapter Two concluded by setting out the types of evidence required to adequately examine the discursive construction and role of morality in talk about medicine taking. This chapter will now detail the methodological framework required to plan the collection of these data, focusing on the properties of talk within interactions around prophylactic medicine taking and how wider social systemic influences might structure that talk.

The view of talk within a social space taken within this study also means having to define the boundaries of that social space, as different definitions of these spaces will differently define the context in which talk is produced, with important implications for what counts as data and what insights are enabled. For example, an analysis of talk within interactions from a conversation analytical (CA) perspective (Atkinson & Heritage, 1984), typically adopts a view that the only context pertinent to the analysis is that to which participants orientate their talk within interactions. It is this context which the analyst will also access, although some attempts have been made to combine CA with macro processes in health research, such as Silverman's studies of the discourses of counselling (1997). Conversely, an analysis of structural discourse, such as in Critical Discourse Analysis (CDA) (Fairclough, 1995), typically views context as linguistic, macro-discourses that regulate the meanings made available within any particular discursive framework, including interactional talk. Whilst these perspectives have very different analytical foci and assumptions, both view context as largely restricted to

identifiable linguistic forms. The present study's methodology, informed by both CA and CDA approaches to discourse, builds on this linguistic focus to enable a view of context unavailable to a solely linguistic analysis, by also incorporating ethnographic features in the production of talk. Such features may be crucial in shaping participant's talk.

This chapter begins by explicating the methodology used in this study and the analytical tools applied to understanding the discursive construction and role of morality in participants' talk. The related details of the participants and methods used for data collection are then discussed as well as the ethical considerations in conducting these methods.

### **Methodological Tools – Discursive Psychology and Linguistic Ethnography**

Three different methodological threads have influenced the design of the methodology in this study. First, and central to this methodology is the discursive psychological approach of Potter, Edwards and Wetherell (Edwards & Potter, 1992; Potter & Wetherell, 1987) to the study of fact construction in interactional talk. Applying discursive psychology (DP) enables us to examine interactional talk about health and illness and to reveal the moral agenda implicit in constructions of medicine taking. Second, understanding how the talk of participants has come about requires some evaluation of the uses of discursive psychological tools for understanding how moral discourses of medicine taking may be activated and how they structure the talk within interactions. This involves setting out the view taken in this study, of the relationship between systemic discourses and individual utterances, specifically the role of power in regulating meaning to examine how far the tools developed in the DP approach may meet these ends. Third, this discussion of power raises questions not only about how power regulates meaning but also in what circumstances power is manifested.

Approaches such as CDA have sometimes been accused of being over-prescriptive in interpreting the role of institutional discourse (Blommaert, 2005), potentially missing important ethnographic contextual features that offer very different interpretations into the production of talk in institutional settings not amenable to a linguistic analysis alone (Collins, 2009; Collins, Drew, Watt, & Entwistle, 2005; Mehan, 1996; Sudnow, 1967). The recent development of linguistic ethnography (LE) (Rampton et al., 2004) in the UK now offers a range of potentially useful methods, some of which have contributed

to the present study methodology. As will be seen in Chapter Five, LE can be used to specify the conditions of power and morality within research settings and to help explain the deviant cases discussed in Chapter Five.

### **Applying Discursive Psychology to Interactional Talk about Asthma Management and Medicine Taking**

Discursive psychology (DP), emerging in the 1980s, is one of many forms of discourse analysis reflecting theories of language developed between the 1950s and 1970s. The review by Edwards and Potter of DP (Edwards & Potter, 1992, p. 27) traces the theoretical origins of discursive psychology to the linguistic philosophical reworkings of language and knowledge (Austin, 1962; Wittgenstein, 1953), cultural and literary theory which studied texts as constructed and active (Barthes, 1974; Derrida, 1976; Shapiro, 1988) and the functional approaches of language use seen in speech act theories (Grice, 1975; Searle, 1969) and ethnomethodology (Garfinkel, 1967; Heritage, 1984). These traditions themselves constituted part-responses to criticisms of Noam Chomsky's theory of the rules of generative grammar developed in the 1950s. A key principle of generative grammar was that a limited set of rules are responsible for generating grammatical sentences. Whilst hugely influential in our understanding of language learning, Chomsky's theory was criticised for not adequately accounting for naturally occurring talk with all its ungrammatical complexity as used in particular contexts (Lyons, 1967).

#### ***Viewing talk as social action***

The disciplinary approaches to studying discourse which emerged from these criticisms developed distinctive views and definitions of discourse analysis while sharing assumptions about the role of language; that text and talk are constructed within social spaces, within and between people, social groups, institutions and cultures; that text and talk does not merely convey information but serves specific functions; and hence text and talk constructs reality through language. These ideas greatly influenced the sociology of scientific knowledge (Ashmore, 1989; Gilbert & Mulkay, 1984; Potter & Mulkay, 1985) and applications to social psychology (Potter, 1984; Potter & Wetherell, 1987; Potter & Wetherell, 1988).



The application of DP in this study has origins in the theoretical critique of social psychological notions of attitude by Wetherell and Potter (1987). This critique was based on Austin's philosophy of language and his notion of the "speech act", which fundamentally changed notions of descriptive talk or text as straightforwardly and accurately reflecting an objective reality. Austin (1962) rejected logical positivist arguments, linked (although perhaps incorrectly) from Wittgenstein's "Tractatus Logico-Philosophicus" (Wittgenstein & Ogden, 2003) that statements which could not be evaluated as either true or false are meaningless and therefore that truth and falsity are critical in an understanding of language. Instead, Austin argued that language does not just describe something but it also does something. This was therefore a radical shift from the conceptualisation of language as something which was logical and which could be assigned a reality. Wittgenstein's later work "Philosophical Investigations" (Wittgenstein & Anscombe, 2001) critiqued both the basic assumptions of logical positivism and also Tractatus, by viewing language-use in everyday contexts, using the term "language games" to emphasise the contextual functions of language use in public space. In a similar way, Austin's philosophy of language reframed language as a human activity within a social context. Rather than viewing individual talk as a way to uncover the internal reality of individual attitudes, he asks us to understand what social actions language performs.

This alternative view of everyday language as a form of social action formed the basis for DP. Potter has argued (2008, July) that DP can be understood as re-specifying many traditional social psychological concepts, namely: memory, attribution, script, attitude, categories. Such re-specification happens when the language used to articulate these concepts comes to be seen as a form of social action. As discussed in Chapters One and Two, much evidence shows how peoples' discussions of health and illness do not just report their memories and attitudes but can also be seen to orientate towards a specific interactional moral agenda. As Radley (1993) argues, in his analysis of the role of metaphor in people's narratives of adjustment to chronic illness, the illness experience is not just about the person meeting the physical requirements to participate in society but is also about arranging the detail of their lives to avoid stigmatization. Their health-related actions therefore need to be legitimated in dealing with other people, to avoid moral condemnation (Bredmar & Linell, 1999; Hassin, 1994; Lawton et al., 2007; Lee, 2007), and to achieve a status that does not separate them from "normal" health status.

### *Talk as sequentially and rhetorically situated*

The key conceptual notion of attitude critiqued in this study, is therefore re-specified not as an articulation of internal cognitive state but as situated linguistic action. As such actions take place within interactions, the “attitudes” that people adopt should therefore be seen as constructed sequentially as participant’s talk unfolds. This view of the sequential construction of talk within discursive psychology relates closely to the central assumption of conversation analysis (Sacks, Schegloff, & Jefferson, 1974; Schegloff, 1968). In this view, health narratives, or accounts are therefore analysed as part of a conversational sequence rather than as a representation of broader variables. In addition, CA analysts also view accounts as a hallmark of “dispreferred seconds”, in other words a response to a question which does not meet the preferred or expected response. When an expected response is not provided in an interaction, there is a conversational requirement to explain and justify the alternative provided. Accounting for one’s health, illness and related attitudes can therefore be seen as situated not only sequentially but also rhetorically. In Chapter One an example of this could be seen in Horton-Salway’s extract from the account of Angela and Joe discussing the causes of ME. The discursive work that they undertook in relating their account could be seen as a sequential and mutual process between Angela and Joe to construct and validate Angela’s ME as an organic condition. People, in “expressing an attitude” towards a health issue can therefore be seen to justify the position they take towards this issue. Billig (1987) argues that we can only view attitudes in a context of debate and conflict, arguing that an “attitude” is an expression of “for” something and “against” something else. This view of “attitudes” seen in a context of debate and conflict shifts the researcher’s analytical attention from what individual attitudes may be to what expressing attitudes does: the interactional functions those expressions serve; the interactional conditions in which those attitudes are manifested (i.e. why this attitude and not another); and how those attitudes are constructed and legitimated.

### *Variation in talk*

Viewing talk about medicine taking as both sequential and rhetorical suggests that an articulated view about illness or medicines, rather than being seen as a consistent and accurate representation of the individual’s attitude, may instead be seen as distinct to specific interactional demands. This raises the possibility that talk about illness

management might vary according to different interactional contexts. Such discursive variation in talk about health and illness has already been highlighted in a range of research (Crossley, 2002; Gillies & Willig, 1997; Radley & Billig, 1996) and these insights may be applied to how talk about asthma is commonly reported. People with asthma are frequently seen to “minimise” and “normalise” the impact of asthma in their daily lives (Adams et al., 1997; Protudjer et al., 2009; Prout et al., 1999). However, within examples of this “minimising” talk participants can be seen to display both dependence and independence in managing their asthma and using medications. Researchers aiming to identify some internal reality of participant’s attitudes and understanding have to reconcile such contradictions if they are to succeed in upholding any decontextualised “attitude” or “understanding”. By contrast, a discursive psychological study will recognize and attend to these contradictions as situated and diversely co-existing social and moral actions. People with asthma can be seen in articulating such normalisation talk to orientate to more widely circulated moral discourses which demand that speakers be simultaneously understood as both responsibly managing their condition and also as people who are demonstrably fit to participate in society. Realising these twin aims can therefore lead to observed shifts in descriptions of asthma medication-use (Protudjer et al., 2009) and to pose potential interactional dilemmas when these different moral agendas appear incompatible.

### **Analytical Tools to Examine the Construction of Talk about Medicine Taking**

People can be seen to deploy a range of devices in justifying their attitudes and behaviour (Potter, 1996). The analytic focus in this study aimed to uncover some of these devices in participants’ talk about medicine taking. Using DP to examine how people justify attitudes and behaviour, allows us to specify some analytical tools which might be useful in interpreting the devices participants’ deploy in constructing versions of events and themselves. We are then able to examine how these devices are deployed in the analysis of participants’ talk. The main analytical tools which were considered useful in this study to analyse the role of morality in participant’s talk were discursive objects and interpretative repertoires and the rationale and definition of these tools are now discussed.

### *Discursive objects*

A key critique that Potter and Wetherell made of attitudinal research relates to how people construct “objects of thought” (1987, pp. 43-55) in their accounts and the term “discursive objects” used in this study, was based on such a critique. “Objects of thought” is a term that has been used in social psychological theories of attitudes to refer to established categories with often taken-for-granted meanings, and attitudes as a manifestation of individuals locating these objects on “dimensions of judgement” (McGuire, 1985). However, Potter and Wetherell demonstrated how people’s construction of such objects can vary even for one person within one interaction. In this study, diagnosis of asthma may well be seen as a commonly-used object of thought in justifying medicine taking. Research on the perspectives of people with asthma has repeatedly highlighted how asthma is viewed in a range of ways including: “not proper asthma;” the sort of asthma not warranting close management; (Jones et al., 2000); a chronic condition; “not an illness” (Adams et al., 1997); an acute episodic condition (Halm et al., 2006). These versions of asthma are typically treated as distorted perceptions of an objectively fixed category of “asthma” founded in scientific, biomedical evidence. However, there is plenty of evidence that demonstrates how people can be seen to actively construct illness and health (Bury, 2001; Charmaz, 1990; Frank, 1995; Yoshida, 1993) to enable their participation in everyday life, suggesting that these non-medically-based versions may be more socially acceptable within important everyday settings such as work. This insight therefore repositions different individual’s versions of asthma as constructions that are critical to dealing with everyday interactions and gaining access to activities within lifeworld contexts, rather than to be viewed merely as distorted perceptions.

Consider the following extract, taken from a qualitative study on asthma which found that families construct a sense of “ordinariness” in managing their child’s asthma, with prophylactic inhalers seen as enabling rather than inhibiting ordinariness: “It’s a firm twice a day commitment that she [my daughter] is supposed to fulfil...” (Prout et al., 1999, p. 150). The findings of Prout et al clearly resonate with theories that emphasise the active construction of illness within lifeworld settings. However, we can build on this insight of the individual as active agent if we examine this extract from a rhetorical perspective. The parent’s use of “firm” positioned them as taking responsibility for implementing what is “supposed” to be done. This can be seen as a response to a moral

discourse having been deployed, that parents are not “good parents” unless they actively ensure that the advice of doctors and nurses is followed. They need to affirm that their daughter has to “fulfil” this “commitment;” and that they have entered into an agreement with their parents in the same way that they might enter into any other parental child arrangement where a task has to be performed. Within the context of being interviewed by a health researcher on how families manage a chronic illness, inevitably a number of issues will be invoked which centre around both the appropriate behaviour of the child and of the parents. This relates to whether their child’s condition may be considered to be physiologically under control and also that the family is a healthy environment for a child with asthma to live in. Their actions are laid open to public criticism and appraisal and so they are unlikely to be willing to depict their child’s asthma as anything other than ordinary and normal and their child’s medication-use as anything other than compliant and responsible. By analysing the lexical and grammatical features used in constructing this statement, the parents’ talk can be seen as enacting the medical directive on asthma management which upholds adherence to prophylactic medications as morally responsible. In addition, their talk could also be seen as positioned within broader cultural and moral discourses of responsible parenthood and child protection.

The same objects of thought are potentially constructed in a range of ways by individuals to perform different functions and with reference to different consequences of blame and accountability. Different lexical and grammatical features may be deployed by speakers to construct these different versions of the “same” object. Within talk about how individuals manage their condition, the construction of asthma, does not reflect an internal reality which may be viewed as distorted, but can also be seen as a flexible device which a person can use to enable them to be understood in particular ways. In this sense we can view these objects of thought as discursive constructions, which speakers act to situate within different moral and culturally-available discourses of illness management. By deploying discursive objects as an analytical tool we may therefore gain insight into the moral discourses that structure talk about medicine taking.

### *Interpretative Repertoires*

Another tool which may help in understanding the role of morality in participants' talk is the "interpretative repertoire". This has been described by Potter (1996, pp. 115-116) as "systematically related sets of terms, often used with stylistic and grammatical coherence, and often organised around one or more central metaphors". In Chapter One, the concept of interpretative repertoire as set out in Gilbert and Mulkay (1984) was introduced to help set out specific differences between social cognitive and discursive conceptualisations of talk. Gilbert and Mulkay noted an asymmetry in scientists' explanations of their own and others research findings (the empiricist and contingency repertoires respectively). This discursive variation indicated not only the rhetorical nature of these scientists' talk but also the use by the same person and in the same interaction, of very different explanations when discussing the same topic. In the present study, "interpretative repertoire" is used to refer to the sorts of explanations that participants provided regarding their medicine taking and in so doing to emphasise how this talk can be seen as social action rather than as reflecting internal attitudes.

However, interpretative repertoires, like discursive objects, were viewed in this study not only as products of interactions but also as regulated constructs set within wider structural discourses of chronic illness management and medicine taking. The reason why explanations that people provide in their accounts may often be seen as rhetorically convincing is that the devices they use tap into commonly understood explanations. Consider the following three examples from the study of older people and discussions of medication-use by Lumme-sandt, Hervonen and Jylha (2000). Lumme-Sandt *et al* identified three interpretative repertoires in the talk of their participants: moral; patient; and self-help repertoires. We can examine examples of each these repertoires for how the speakers enacted versions of moral, culturally-available discourses of illness management to account for their medicine taking.

The following first example was reported as belonging to the moral repertoire: "All I have on prescription are these children's aspirins and even they are for dizziness" (2000, p. 1846). Lumme-Sandt *et al* argued that there is a strong moral dimension in this type of talk which orientates around the speaker's need to minimise and to offer justification for their use of medications. Presenting medication-use in this way serves to present the speaker as morally responsible in the management of their illness, deploying the same kind of minimisation talk seen earlier in talk about asthma medications. However, we

can also see a moral dimension in both the patient and self-help repertoires reported in the study by Lumme-Sandt et al:

*Patient repertoire:* “I only have these doctor's prescriptions. Six different ones in the morning and three in the afternoon” (2000, p. 1847)

*Self-help repertoire:* “I have used onions all my life and I now use flaxseeds and parsley as medication and they are good. These are my drugs”. (2000, p. 1847)

As Lumme-Sandt et al report, the talk identified within the patient repertoire is set within the role of the compliant and satisfied patient. We can therefore see a moral incentive to position oneself as a “good patient” within what might be called a discourse of Parson’s “sick role” (Parsons, 1951). In contrast, we can see a very different moral discourse being orientated to in the self-help repertoire. Here the speaker can be seen to be positioning themselves as actively engaged, not dependent on medications and therefore a fully engaged, responsible manager of their health. This is not necessarily a responsibility set within a medical perspective but instead sitting comfortably within an alternative lifeworld perspective about what it means to be responsibly engaged with life, health and oneself. The object “drugs” can also be seen to be discursively subverted in a way which also alludes to these alternative therapies, thereby positioning the speaker as compliant within such an alternative discursive paradigm of healthy lifestyle choices and illness prevention.

“Interpretative repertoires” then can be viewed as orientating to versions of discourses that circulate shared social spaces and which will be appropriated by speakers to perform specific functions within interactions. In the present study, such functions are viewed as moral actions and both interpretative repertoires and discursive objects are seen as linking the detail of rhetorical talk to wider moral discourses of chronic illness management and medicine taking. The DP approach adopted in this study enabled these links to be made by focusing on the lexical items and grammatical styles that people use to construct discursive objects and interpretative repertoires that position their attitudes and versions of behaviour within wider moral discourses.

By asking people with asthma questions about medicine taking, in particular, people who have not taken prophylactic medications as prescribed, the researcher places demands on the responder to orientate in some way to the medical directive to follow

the instructions of those medications. Even if the “responder” says nothing, their “non-response” tells us something about how, within the conditions of the research interview, that person does or does not engage with the medical agenda that preventive therapies need to be taken regularly if asthma control is to be achieved. This interactional dynamic therefore locates this interaction, institutionally within a research and health context and, historically, within a contemporary context of reducing risky lifestyles, preventing chronic illness and prophylactic medicine taking. This talk is highlighted as sequential, rhetorical and interactionally-constructed and regulated by wider moral discourses. This tension between the constructed and constructive nature of talk reveals important issues of power in talk relating to medicine taking. We may now briefly draw on some theories about the exercise of power in talk in order to theorise how moral discourses of medicine taking may circulate to different social spaces and to the talk of the participants in this study.

### **Issues of Power and Structuring Talk about Medicine taking**

In Chapter Two the language presented in asthma guidelines was linked to talk produced within interactions. An argument for a moral discourse of asthma management could therefore be constructed, regulating what clinicians and patients are able or willing to say about taking prophylactic medications. This argument reflects Foucault’s use of the term “abstract discourse” in the “Archaeology of Knowledge”, a term typically used when referring to sets of related statements that are identifiable as regulated and produced through the practices of specific institutional frameworks (Foucault, 1972, p. 121).

In the asthma guidelines such discursive statements may be grouped together as “recommendations” or “best practice” which offer a limited range of options, typically a regular pharmacological treatment, and which decisions about patient’s asthma management have to conform to. It may be argued that the implications of this asthma management discourse for clinical practice is that talk of treatment options within clinical consultations is limited to statements that refer closely to these guidelines. The relationship between systemic discursive structures and the regulation of meaning has preoccupied generations of scholars and can be understood within theories on the function of “soft power”, set out by Gramsci (1891-1937) in *Prison Notebooks* (Gramsci, Hoare, & Nowell-Smith, 1971). In contrast to the coercive and violent notion



of “hard power”, “soft power” refers to winning “hearts and minds” (J. Blommaert, personal communication, November, 2007), the acceptance and popular support of rulers by the ruled. To gain such popular acceptance the language of propaganda is exercised, and an essential component to this propaganda in gaining societal control is Gramsci’s concept of “hegemony”. This refers to the “intellectual or moral leadership”, the creation of an ethics or morality by state institutions, an “ethical state”, backed up and enforced by the capacity to use coercive, or “hard power”.

Fairclough’s (1995) approach to CDA draws links between hegemony and discourse that are of key relevance in addressing the impact of institutional morality in the talk of people with chronic illnesses. He argues that discourse conventions (as within a doctor-patient consultation, or a job interview and even a research interview) naturalise particular ideologies of the participants and relationships within that setting, (doctor-patient, researcher-participant), particular types of knowledge and beliefs and attitudes and so, appropriate or inappropriate behaviour, within and outside that environment. In the case of people with chronic illness, the naturalisation of discourse surrounding the doctor-patient relationship and discourses of illness management will involve following medical advice, typically through the use of prophylactic medications. Naturalising these discourse conventions, Fairclough argues, enables the ideological dimensions of existing hegemonies to be reproduced.

This naturalisation of discourse within institutional settings has clear links with Bourdieu’s notion of “habitus”. Bourdieu (1984, pp. 169-225) argued that individuals incorporate social structures in every “habitual act” including speaking and writing. The notion that certain types of talk are naturalised and habitual in institutional settings implies that certain other types of talk will be considered unacceptable, irrational or even radical. In the context of talk about medicine taking and in view of the recommendations set out in guidelines for the treatment of asthma, choosing prophylactic medications are presented as natural and habitual whilst other “alternative” forms of therapy/decisions may be considered irrational, radical or simply incorrect. As seen in the analysis of these guidelines in Chapter Two, such alternative decisions are not easy to take and are monitored: “*significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient’s case notes at the time the relevant decision is taken.*” (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2008 revised June 2009, p. iv1)

Whilst this research draws on theories of power, it also queries how we can identify the evidence for this. The risk of taking a pre-determined view on power is that this will fix the role of structural discourse and presume that participants within a particular institutional setting will always orientate to institutional notions of moral behaviour constructed as a hegemonic and discursive practice. Conversation analysis of interactional data in institutional settings has revealed how the exercise of power should not be taken for granted (Silverman, 1987; Thornborrow, 2002) and there may also be “asymmetries” (ten Have, 1991) in the amount of talk and the style of turn-taking available for roles within institutional settings and activities. These do not necessarily entail a power imbalance, they may just be inevitable aspects of “expert-provider” and “layman-listener” roles. Power dynamics therefore have to be identified rather than assumed within a micro-analysis of data. The present study adopts an approach which attempts to avoid being prescriptive about how discourse is manifested and what function it serves. Power may be accepted or resisted and may have its origins in multiple locations. An example may be taken from the analysis of accounts of health and illness by Radley and Billig (1996):

Wife: ‘He didn’t rest as much as he should have done. There’s no doubt about that. That used to bother me. He used to go out pottering about in the shed and doing things that I didn’t think he should do. I can’t remember anything in particular.’

Husband: ‘Like chopping sticks one afternoon – all afternoon, while she was at work.’

Wife: ‘There’s no holding him when he’s alright!’

Husband: ‘Another time I was splitting logs for an hour.’

Wife: ‘That was naughty too!’

Husband: ‘Some people would say it was too much, but I thought it was getting me better quicker....And I felt that the more exercise I did the quicker I got better.’ (Radley & Billig, 1996, p. 227)

The analysis by Radley and Billig of this extract emphasised the potential for seeing the production of the story of the husband’s behaviour as a joint activity in reproducing their shared memory. Radley and Billig also discussed how the account provided by the husband and wife was situated within a discursive framework of gender relations and

moral order with the husband emerging as the “victorious hero” and the wife the “worrying female”. Radley and Billig argued that this sequence is typical of how people, who are considered ill, draw on versions of health in their accounts to negotiate themselves out of weak positions of ill health which, if we view from with a Parsonian “sick role” discourse, evades their social responsibilities and their place in the social order. The husband, in his activities, not only provided evidence of how he was responsibly overcoming illness, but with the help of his wife, also asserted his place within a traditional discourse of gendered roles. The activation of the sick role discourse in this account was not pre-determined or fixed, with the husband being designated an inevitable place within medical notions of good and bad patients. Instead, the husband and wife’s version of the sick role worked simultaneously in conjunction with a cultural discourse on gendered roles, and positions were negotiated as their story developed. These positions can be seen to be in turn: “naughty”; irresponsible activity for a person with this illness; a sensible risk-taker; a person doing manly activities like chopping wood; heroic. Again talk about health and illness can often be seen to involve orientating to and undermining contesting alternative interpretations of behaviour “some people would say it was too much, but I thought it was getting me better”. (Radley & Billig, 1996, p. 227)

This complexity in referential meaning relates to the contextualised function and orientation of interpretative repertoires analysed in this study in talk about medicine taking; that there are no rules about who uses different repertoires and when, and they will be used flexibly to perform particular functions within specific interactional demands. The same speaker can assume different voices or “footings” (Goffman, 1981) and thus, it can never be assumed that the same type of talk refers to exactly the same meaning. Interpretative repertoires and discursive objects are concepts used in this study to capture this relationship between structural, abstract discourses such as the sick role discourse, and the constructive properties of interactional talk.

If a proposition, a sentence, a group of signs can be called “a statement”, it is not therefore because, one day, someone happened to speak them or put them into some concrete form of writing; it is because the position of the subject can be assigned. (Foucault, 1972, p. 107)

The approach taken in this study treats what people say about chronic illness as not necessarily submitting to the dominant morality of medical notions of appropriate illness management, but, rather, to suggest that participants may manage several moralities simultaneously. These moralities may originate and circulate through a range of social spaces and as explored in Chapter Two, may be particularly pertinent in participants' everyday lives, their lifeworlds (C. I. Salter, 2005; Schutz, 1962) to play a key role in their decisions about medicine taking. The DP approach and associated analytical tools discussed in this chapter will be applied to the data in Chapter Four to gain insight into these moral manifestations in participant's talk.

### **The Distribution of Interactional Resources in the Construction of Moral Talk about Medicine Taking**

So far, the need to demonstrate rather than assume the role of moral discourses in talk, has informed a methodological framework facilitating insight into participants' orientating towards multiple moralities in their talk about medicine taking. However, while these analytical tools may enable a path to be traced from systemic, cultural discourses to individual utterances, they have limited ability to specify the circumstances in which such talk might occur and their moral implications, as will be seen in Chapter Four which describes the analysis of interview data. Chapter Five, will go on to examine the absence of moral discourses in participant's talk in relation to the presence or absence of resources that members of interactions may have had available to them. Misunderstandings within interactions have been found to highlight inequalities in access to resources which may importantly affect how that interaction proceeds. Consider the following example from a study of misunderstandings within primary care consultations (Roberts, Moss, Wass, Sarangi, & Jones, 2005).

Here, a Bangladeshi patient has come to ask his GP to sign his passport form.

- |   |   |   |
|---|---|---|
| 1 | D | black pen and this is for you M isn't it                        |
| 2 | P | yeah M B's my name  |
| 3 | D | <b>how long have I known you B</b>                              |
| 4 |   | <b>(1.5)</b>  |
| 5 | P | <b>my name</b>  |
| 6 |   | <b>(..)</b>   |
| 7 | D | <b>How long (0.5) how long do I know you for how many years</b> |

8 P oh:um (..) e::h 9 years (..) come to the re- I come to this country  
9 in er (.) 1990(.) but [then I am]  
10 D [I saw you] in ninety: six  
11 P 96  
12 D (0.5) ((counts on fingers of left hand)) 5 years I've known you  
13 (.)  
14 P really

Roberts et al highlight in relation to this extract, how the text in bold represents a crucial misunderstanding in the interaction between the doctor and patient with important implications for how the consultation continues. The causes of the misunderstanding are evident on a number of levels: phonetically, (“known” and “name”); grammatically, (have known vs. do know); metaphorically (how long..?); bureaucratically (the use of the expression “how long have I known you” within this bureaucratic context); and institutionally, (the patient may not appreciate that to sign the passport the GP must have known the patient for a minimum length of time). The consequence for misunderstanding within this sequence is that the doctor has to reformulate the spatial metaphor “how long have I known” from the present perfect to the present tense which then elicits the required response.

Whilst the focus of the research by Roberts et al was to identify some specific reasons for misunderstandings between GPs and patients from diverse language and cultural backgrounds, important insights can also be drawn from their analytical findings which may be applied to any instance of interactional talk within institutional settings. Such talk has the potential to involve misunderstandings within interactions when there are mismatches in how members of those interactions understand that talk, even if members might be regarded as speaking the same first language or from similar cultural backgrounds. These misunderstandings are likely to occur for a variety of reasons, but as seen in the extract from the data of Roberts et al, may be located in inequalities in members’ access to key linguistic, bureaucratic and institutional resources. Members’ understandings of the meaning of an interaction and the talk within it therefore has consequences for how those interactions proceed, with important implications for analysing the role of moral discourses in talk about medicine taking.

The production of naturalised institutional talk referred to by Fairclough, which in the present study involved examining the production of medical notions of appropriate illness management in talk about medicine taking, may depend on how the members of that interaction understand what that interaction is about. The activation and sequential development of moral discourses of medicine taking within such talk may be reliant on members having access to and interpreting the interaction as pertinent to that discourse. If interacting members do not share understandings of the talk taking place within that moral discursive framework then the interaction is likely to proceed very differently to other interactions where that discourse is considered relevant and available to both or all participants. Chapter Five will examine whether differences in understanding about the meaning of interactions may be linked to the distribution of resources related to participants' involvement in the study and discuss the implications of potential differences for the production of moral discourses of illness management and medicine taking.

However, the analysis of Roberts et al indicates that while misunderstandings may be manifested within interactions, insight into the distribution of resources within interactional talk is enhanced by moving beyond the evidence solely available to a linguistic analysis. This may mean looking beyond specific interactions to other contextual features that may influence that interaction. To understand these contexts, ideas and techniques were drawn from linguistic ethnographic approaches to communication and language.

### **Linguistic Ethnography**

Linguistic ethnography, which has emerged in the UK in the last 10 years, has been described as a site of encounter for different disciplines and perspectives, rather than a conceptually-unified school of thought (Rampton et al., 2004). Whilst those associated with LE conduct their work from a wide range of disciplines, these scholars have come together in order to help resolve some common difficulties identified in the analysis of text and talk, particularly with regards to communication. A central area of difficulty lies in definitions of context, how context is investigated and what implications these issues have for how power can be seen to operate in text and talk. LE forums in which the analysis of communication have been explored, have generally agreed that important contextual influences on communication can be seen as both ethnographic and linguistic

and that context should be investigated and not assumed. Ethnographic and linguistic approaches to communication have often been seen to work as separate disciplines and as a consequence have potentially missed opportunities to draw on respective strengths in answering similar research questions regarding communication. LE has drawn on a range of theories, methodologies and analytical techniques to apply to studies of communication and to help generate new insights about the production of talk and how we might better go about analysing communication.

Rampton describes LE as an attempt to “tie down” ethnography and “open up” linguistics. Such opening up of linguistics has particular relevance to the methodology constructed in this thesis at this point. Incorporating ethnographic analytical techniques into an otherwise linguistic approach offered the potential to provide important insights into important contextual features that might otherwise go unnoticed, offering techniques to move beyond research interview transcripts to examine those processes and steps that influenced the research setting, vital in an evaluation of the discursive work taking place.

As indicated by the data of Roberts et al, sequences of interaction follow from those resources available to members of interactions. To follow a particular interactional pattern, the appropriate linguistic resources need to be activated. When the appropriate resources are not easily accessible for member(s) of interactions misunderstandings may occur, indicated by a different interactional pattern. Similarly, the prevalence of individual justification and morality in talk about medicine taking may depend on participants having access to and deploying particular moral discourses in their talk. Moral talk about prophylactic medicine taking was therefore examined while taking account of participants’ available resources, working towards an understanding of when moral discourses of medicine taking may be likely to be activated.

Understanding resources available to participants within the present study meant looking at how participant’s understandings could be seen to be manifested in the specifics of language produced, i.e. the rhetoric of the talk, moments of tension in turn-taking sequences and interactional patterns which suggested different resources and mismatches in interactional framings. However, to seek insight of how these understandings came to be manifested also required the author to examine the conditions that led to the research setting – the process of selection, eligibility and

recruitment, any documents used, the research setting itself, the roles that were constructed as well as how the data were captured, recorded, transcribed and interpreted.

The analysis of data in Chapters Four and Five will therefore move from an analysis of rhetoric and moral discourses in researcher-participant interactions, to an examination of researcher and participant presuppositions, activity types within the research interaction, multi-modal constraints within the interaction and an examination of how participant's identities were constructed and transferred across contexts prior to interview. This aims to enable specific insight into the interactional conditions in which participants deployed linguistic resources that orientated to moral discourses of medicine taking.

### **Methods, Data Collection and Participants**

The study was carried out as a qualitative sub study linked to a large, quantitative asthma study (ELEVATE). The ELEVATE study consisted of two randomised controlled trials (Step 2 and Step 3 trials) with almost 700 participants. The qualitative sub study was linked to the Step 2 trial and each participant, upon entering the study, was allocated either an inhaled corticosteroid inhaler or a leukotriene receptor antagonist tablet. These participants were considered to have mild to moderate asthma upon entering the Step 2 trial.

#### ***Details of recruitment to the qualitative and quantitative studies***

The steps involved in identifying and recruiting participants are now described. This includes documenting the steps to recruitment for the quantitative study set out in the final report for this study (Price et al., in press), extracts of which are included in Appendix C. The summary account given here has edited the full report of these steps to provide only those details needed to contextualise the study of the present thesis, omitting some of the technicalities relating to medication type and asthma severity. Full documentation of these is available in the full report of the ELEVATE study.



### *Recruitment Stage 1: The Asthma Control and Quality of Life Questionnaire*

People who might be eligible to participate in the ELEVATE study were identified by searching the electronic databases of General Practice medical records. These were patients aged 12 to 80 years attending 53 participating GP practices in Norfolk, Suffolk, Essex, Cambridgeshire, Bedfordshire, Hampshire and Dorset. Patients were asked to complete and return to their GP practice, two questionnaires (both disease-specific validated tools): the Asthma Control Questionnaire (ACQ) used to evaluate asthma control (Juniper, O'Byrne, Guyatt, Ferrie, & King, 1999); and the Mini Asthma Quality of Life Questionnaire (MiniAQLQ), (Juniper, Guyatt, Cox, Ferrie, & King, 1999), used to evaluate the impact of asthma on quality of life. Patients who met the entry criteria (see Appendix C) were invited for a screening visit (Visit 1).

### *Recruitment Stages 2 and 3 - The ELEVATE study Visits 1 and 2: Assessing eligibility and entry into the randomised controlled trial.*

At Visit 1, participants (and parent or guardian if appropriate) gave written informed consent and were allocated a unique study number. Participants were given the option of consenting to interviews and some brief details were provided in addition to the main information and consent forms, (see Appendix C).

The nurse reviewing the patient's asthma made a clinical judgement about the potential benefit that the patient might receive from taking an additional medication based on a combination of objective measurements commonly used in the assessment of asthma control and quality of life. This nurse assessment was conducted at Visit 1 and Visit 2, which took place 2 weeks after Visit 1. All patients later entered into ELEVATE were therefore considered likely to benefit from additional treatment to control their asthma and improve their quality of life. Eligible patients were randomised according to their asthma severity and current medication-use. The patients recruited for qualitative interviews would have been allocated one of the two prophylactic treatments for their asthma being comparatively tested in the Step 2 quantitative trial: a corticosteroid (brown) inhaler or a leukotriene receptor antagonist tablet.

### *Recruitment Stage 4 - Analysis of prescription records for evidence of history of non-adherence*

The qualitative study, focused on the insights offered by those people who had been entered into ELEVATE as likely to benefit from taking a prophylactic medication regularly but who had not previously taken this medication as prescribed. By implication, by not following the instructions of that treatment these people could be considered as “non-adherent”.

Patients were identified from prescription records, who had been prescribed the standard prophylactic therapy, inhaled corticosteroids prescribed in the previous year, but who, according to the standard dosage and frequency of use given by the British Thoracic Society guidelines (2008 revised June 2009, p. 36), did not appear to be taking it regularly.

*Recruitment Stage 5 - Telephone call to check non-adherence to inhaled steroids and invitation to participate in interviews.*

Each participant potentially eligible for the qualitative study was telephoned to discuss the details of the research interview, to invite them to take part and to gain further information on how they did or did not use their brown inhaler prior to entry into the ELEVATE study. Prescription refills and adherence self-reports as indicators of adherence have generally shown to be unreliable in research studies (Christensen, 2004) which have also found a general trend of patients overestimating rather than underestimating their adherence to medications. Any admission by the person of non-adherence was therefore considered as a potentially eligible participant for the qualitative study. An interview was set up if participants appeared to have a history of non-adherence and agreed to take part.

A confirmation letter was then sent to participants with details of what the interview was about as well as another questionnaire that has been used to assess patient adherence – the Medication Adherence Report Scale – MARS (Horne & Weinman, 2002), (see Appendix C). However, in the qualitative study, this was to be used to provide a starting point for discussion in the research interview rather than as any intended measurement aid of adherence.

### ***Participants - demographic information and relevance to analysis***

Twenty-four people were identified as potentially “non-adherent” to prophylactic medications and therefore eligible to participate in qualitative interviews. Two further people were identified who had not taken prophylactic medications before entering the study. These people were invited to participate as their talk could potentially provide useful contrasts with the other participants’ discursive strategies. All 26 people had consented to take part in the ELEVATE study and qualitative interviews at visit 1. All participants were white British, lived in Norfolk, Suffolk and Cambridgeshire and spoke English as a first language. Participants were aged between 17 and 80 years. Thirteen were women and 13 were men. Five participants had received a diagnosis of asthma less than three years prior to interview. The participants reported having one of the following occupations: farmer, farm manager, school pupil, retired general practitioner, social services employee, telephone engineer, caterer, housewife, car showroom manager, retired, trainee school teacher, and pub landlord.

### **Data Collection Methods**

Face-to-face interviews and a focus group were the two main methods used to collect data. However, the discursive approach taken in this thesis meant that any instance of language in text or talk could also be treated as data and hence other data sources were also examined in this study which played a fundamental role in understanding the participants’ talk in the interviews and focus group. The Chapter Two review of literature examined text from a variety of additional sources. The moral discourse of asthma management identified in the analysis of asthma guidelines, texts on asthma causation and management as well as sources which did not concern asthma were used in this study to examine how cultural discourses of illness and asthma management might structure the talk of participants in the interviews and focus groups. Similarly, the process by which participants were recruited has also been examined and can be viewed as providing data. The recruitment process set out for the quantitative study offered details of the conditions which preceded the interview and focus group data, and which may have importantly shaped the content and interactional process within these core data. Participant recruitment is therefore analysed in more detail in Chapter Five to address a particular concern about the circumstances in which participants could be seen to justify their medicine taking. These non-interview-based sources of data are crucial in

providing further evidence of what might structure the talk of participants and to situate such talk within a social historical context. However, the selection of these additional materials was not to assert these sources as the only relevant influences likely to structure participants' talk. The production of talk within research interviews would likely have been affected by a multitude of influences. Rather, the choice of these additional materials was based on those which were accessible for analysis, but also those that could be seen as likely to play an important role in the production of talk about medicine taking within the context of participants taking part in an asthma study comparing prophylactic medications.

### ***Face-to-Face Interviews***

Face-to-face, semi-structured interviews were conducted with all 26 participants who agreed to take part in the qualitative component of the ELEVATE study. Interviews were chosen because this study was interested in how people with asthma constructed an account of their asthma management and so interviews provided a means to directly obtain these perspectives. As discussed in Chapter One, seven of these were also interviewed a second time to explore persistence in how they talked about medicine taking at two time points. The second interview took place a year after their initial prescription of the randomised prophylactic treatment and participation in the main asthma trial. For the first interviews, Mason's (2002, pp. 68-74) guide to structuring qualitative interviews was used to construct a flexible interview schedule and a series of "topic cards" to guide the discussion, including: "biography of asthma", "treatments", "relationships and asthma" and "risk and severity" (see Appendix A). Topic cards were used to help the interviewer elicit a mixture of narratives and "attitudes" from interviewees. This talk could then be analysed to examine ways in which medicine taking behaviour and views were situated by participants within a social historical context. An additional interview guide was developed for participants who were interviewed a second time. Topics covered included the participant's story of their asthma since the first interview; views on their asthma and risk; medication-use; life/asthma goals; views of health and illness; experiences of encounters with doctors/nurses; issues of trust in illness management; and the future and their asthma. These changes were implemented following an understanding that the participants' lifeworlds may be fundamental in how they managed their condition. In addition the author was exploring the notion of risk as a relevant issue for asthma and medicine

taking and considered asking participants direct questions about risk a useful way to understand this issue.

Despite the imposition of a structure on participants' talk by the interviewer's use of topic cards, interviews were conducted with the aim of allowing participants to say whatever they felt relevant, following typical guidance on effective qualitative interviewing techniques, which suggests the use of open questions, avoiding imposing the researcher's own opinions and use of prompts to elaborate or clarify (Lincoln & Guba, 1985). Interviews therefore did not rigidly follow a standardised interview structure and in several cases some of the planned topics were not explicitly discussed. Interviews typically lasted approximately one hour, with the shortest interview lasting thirty minutes and the longest about one hour and forty five minutes. Issues typically covered included: the history of the person's breathing condition, events around receiving a diagnosis of asthma, history and habits of using medications and details of communication between themselves and doctors and nurses. However, using topic cards required the researcher to enact some assumptions about the issues that were pertinent to discuss, structuring the talk of participants and hence impacting on the data that were produced. These same issues were also likely to be selected in conducting the analysis as most pertinent to justifying asthma management and medicine taking. The implications of this structure for participants' talk and the data produced are examined in Chapter Five.

### ***Data-Sharing Focus Group***

A single focus group was undertaken with participants from the face-to-face interviews. Within the focus group, data, in the form of anonymous vignettes, was shared with participants. These vignettes were not taken from any single interview but were constructed from the accounting styles that were identified in the initial phase of the analysis of interview data. The rationale for collecting the focus group data emerged as a response to questions raised after the analysis of the interview data about the role the author played in helping to construct the talk of interviewees. The focus group offered a means of addressing these difficulties by obtaining data that was based on a different set of interactional conditions to the face-to-face interviews. The methodological rationale for the development and design of the focus group will therefore be reported in detail in Chapter Six after the analysis of interview data.

## **Ethical Considerations**

Participants were invited to take part in the qualitative sub-study at the same time as being invited to participate in the larger quantitative asthma study. If willing, they provided their consent to participate in interviews at Visit 1 of the ELEVATE study. On contacting the participants to invite them to be interviewed, and at the interview itself, the researcher informed them that the aim of the interviews was to understand their views about their asthma and the medication they had been prescribed in the study. They were also given information to clarify that the research sought to investigate issues that influenced people's decisions to take medications commonly used to prevent asthma symptoms and that this may involve discussing how the patient viewed health and illness in general, lifestyle choices and the person's attitudes to life in general.

Participants were also informed that:

- They could withdraw their participation at any time and without giving a reason.
- The interviews were part of a student project and were in addition to the main study.
- The interviewer had not received any medical training and was not able to offer any advice regarding their asthma. As necessary participants were advised to contact their local surgery if they had any questions regarding their asthma.
- The interviews would be recorded, a transcript generated and that the results of the study would be published in academic journals. All steps would be taken to protect the individual identity of participants in the use of these materials.

After conducting several first interviews the author considered that participants should be verbally re-consented regarding the aims of the interviews. This was because the focus of the PhD study had shifted beyond a specific focus on asthma and medications to the meanings of asthma within a lifeworld context. Re-consenting participants to these study aims was not only to ensure participants understood the researcher's aims but also to facilitate discussions that went beyond a specific focus on asthma. Details of the rationale and steps taken to re-consent participants are provided in Appendix D.

All but one focus group participant had provided informed consent to take part in the quantitative and qualitative studies and had already taken part in the qualitative interviews which preceded the focus group. Before the focus group discussion,

participants were reminded both in writing and on the telephone that the aim of the qualitative part of the study was to obtain their perspectives regarding their asthma and medicine taking. They were also informed that the aim of the focus group was to share some of the interview findings and to obtain their views of those findings.

The participant who had not previously consented to take part in the ELEVATE quantitative study, nor had taken part in any other part of the qualitative study, had attended the focus group with his father and was invited to take part. Despite being recruited in a very different way to the other participants, this person could count as an appropriate member of the group discussion when viewing talk about asthma management from a discursive perspective. This is because his talk, like the other participants, could also be viewed as situated within a social historical context in which moral discourses of illness management are circulated to different social spaces. His inclusion therefore offered an opportunity to examine how issues of morality might be manifested differently to the other participants. On inviting this individual to participate, the focus group moderator, and author of this thesis, gave him verbal information regarding the details of the study and purpose of the focus group; his right to withdraw at any time; and that if he took part then his name would not be used in the transcript. The other participants were asked if they minded this individual taking part in the focus group. After the focus group he was provided with further details of the study and was offered, but declined, the opportunity to withdraw his contribution. All participants were also informed that their own views would not be presented in the data, reminded of their right to withdraw their participation and asked not to share personal comments arising in the discussion with anyone outside of the focus group.

### **Summary of Methodological Approach**

Understanding how culturally-available discourses help to structure interactional talk provides a “loose coupling” (Goffman, 1983, p.11) for examining talk about medicine taking. This allows us to consider and discuss the circumstances in which participants within interactions about prophylactic medicine taking may reproduce moral discourses of illness management and which may also influence decisions about medicine taking. To understand how interactional data comes to be structured, the specific approach set out here builds on DP by examining the language used in a range of documents which detail cultural conceptualisations of the causes and management of illness. The language

identified within the review of the asthma and other health and illness literature in Chapter Two provided a range of discursive elements used to construct a moral discursive framework about asthma prophylactic medicine taking that can be seen to be activated in talk and text across time and space. A key source used was the body of contemporary clinical asthma guidelines for asthma management, commonly used by clinicians in asthma consultations. Asthma guidelines are used to regulate and control the allocation of treatments for asthma, so offering the potential to regulate not only clinical and patient decisions about medicine taking but also, by implication, to regulate the talk which governs those decisions. By deploying this methodological tactic, a specific discourse can be seen to circulate the treatment and management of asthma. This discourse of asthma management focuses on the need for asthma control by: drawing on a limited range of therapeutic options; patients monitoring their own symptoms; and adherence to self-management plans which orientate to adherence to prophylactic medications. These parameters of asthma management constructed within this discourse therefore carry important codes of conduct regarding the behaviour and decisions of clinicians and patients which are also likely to regulate the talk related to those actions.

The discourse identified within asthma guidelines can therefore be seen as a moral discourse of asthma management and the core task identified for the analysis of interview and focus group data in this study is therefore to trace a path from this moral discourse to the talk of participants. The discursive psychological tools are useful here because they enable examination of the moral components of talk through an analysis of rhetorical devices that participants deploy. Notions of morality can be seen to be implicit to the rhetorical construction of accounts of behaviour, versions of events and versions of the self. In the present study, accounts of medicine taking are examined in terms of their deployment of a range of rhetorical devices which orientate to the particular discursive issues that are activated within the interactions taking place. Rhetorical devices work not only to present a particular version but also to undermine alternative versions and it is this then-observable discursive work that will indicate the particular notions of morality that speakers are attending to. Two rhetorical devices that have been identified here as likely to be used by speakers in managing competing alternatives are “interpretative repertoires” and “discursive objects”. Reasons why speakers are likely to use such devices and why they may be relevant for the analytical approach taken in the present study are that these devices appropriate culturally



available discourses and objects respectively, are likely to be shared between members of the interaction and can be seen as critical in how blame and accountability are allocated. Moral discourses can therefore be usefully viewed as both constructing and constructive in speaker's accounts with repertoires and objects being used flexibly by speakers to perform specific and sometimes multiple contextualised tasks. However, the nature of this relationship between systemic moral discourses and utterances is not fixed and the analysis of rhetoric in the interview data will examine the limitations of these data for interpreting the role of morality in the talk of participants beyond those interviews. The conditions in which participants are likely to engage with notions of morality in their talk needs to be investigated rather than assumed and it is for this reason that this study has also drawn on techniques associated with linguistic ethnography. These techniques, which originate from a range of disciplines, are used to identify contextual influences on the production of participants' talk, which may not be directly accessible to a more narrowly linguistic analysis. Conducting this task will then provide the rationale to provide data generated on a different set of interactional conditions to the face-to-face interviews. Moving to this developed analytical position provides a basis for evaluating the interactional issues and role of morality in talk about prophylactic medicine taking.

## Chapter Four

### **Analysing Interview Transcripts to Evidence Interactional Issues and Moral Discourses in Talk about Prophylactic Medicine taking**

*I'm not one of these people who get up in the morning and think "right, inhaler, take it (.) before I go to bed, take it"*

(501441, Interview 1, page 3, lines 6 to 9)

This chapter will present the analysis of face-to-face interview data, undertaken to identify evidence of moral discourses influencing participant's talk about medicine taking. Participants may need to justify their asthma management and medicine taking in face-to-face interviews to manage the potential allocation of blame and accountability for their reported views, medicine taking decisions and other actions regarding the management of their asthma. One type of justification participants might attempt, deploying a range of rhetorical devices, is to demonstrate that they are in control of their asthma, potentially deploying historical discourses of asthma causation and management. It is conceivable that some of these discourses might be activated by participants in their interviews with a health researcher in justifying any "non-adherence" to prophylactic medication.

The purpose of the analysis reported here was to identify evidence of blame and accountability in participant's talk and how this may have been linked to moral discourses of medicine taking and asthma management. This will be used to assess the merits of this approach for understanding talk and decisions about prophylactic medicine taking. Analysis of the face-to-face interviews was therefore aimed at identifying interactional rhetorical devices that showed the participant orienting to issues of blame and accountability and how the management of different discursive positions activated in this process linked to culturally-available moral discursive frameworks such as those identified in the analysis of asthma guidelines and other sources in Chapter Two.

The analytical strategy which was adopted to analyse interactional talk began with an attempt to identify patterns in how decisions about taking prophylactic medications

were justified across all face-to-face interviews. This was to provide evidence that a moral agenda in the talk of participants was pervasive in the dataset whilst at the same time also allowing deviant cases to be identified. As will be seen this early analytical approach raised particular problems relating to an attempt to individualise participant's accounts as having a particular style, their "accounting style". A solution to these analytical problems is therefore set out and which prepares the ground for the second area of analysis which examined the properties of talk about prophylactic medicine taking if viewed from a discursive psychological perspective. This highlights the dilemmas that many participants could be seen to be managing in their talk which were intimately connected to notions of blame and accountability. This takes us to the final area of analysis in this chapter which examined the links between participant's management of blame and accountability with wider discourses of illness management.

The analysis of interview data therefore focused on four areas:

- A description of the different ways, referred to as "accounting styles", in which talk about prophylactic medicine taking and asthma management were discussed in face-to-face interviews.
- A demonstration of the properties of this talk, as seen from within a discursive psychological framework and the interactional dilemmas that can be seen to be activated within the interactions for participants.
- An illustration of how these dilemmas are managed by participants and thereby how issues of blame and accountability are managed.
- An examination of the culturally-available moral discursive frameworks that are activated within interactions and which allocate blame and accountability.

Although the majority of participants could be seen in their interviews to be legitimising their medicine taking there were three participants who did not appear to attend to justifying their medicine taking. The limitations of the findings reported in this chapter will therefore be discussed, thus preparing the ground for a further examination of these "deviant" cases in Chapter Five.

## **Analysis of Face-to-Face Interviews to Identify Accounting Styles**

In Chapter One, the primary objective of these early analytical steps was shown to emerge from the need to develop a sample to follow up for a second round of interviews, intended to be used to validate findings from a first round of face-to-face interviews. An analysis of patterns in accounting styles across participants was undertaken to examine how these styles and thence moral discourses of medicine taking deployed by individuals in their first interview may have persisted in their talk in their corresponding second interviews. This sample was to be selected to reflect preliminary categorisations of a limited set of analytically distinct ways which it was intended should cover all participants' accounting for and justification of how they took medicines. However, only 18 interviews from the 26 first interviews were characterised in this way because, in performing this task, significant problems were identified. These were found to relate to the level of analysis being undertaken, to developing understanding of discursive variation within the interactions and the attempt to validate findings using a second interview.

The process for identifying each participant's accounting style is described in Appendix D. To help organise the identification of accounting styles, NVivo software was used. NVivo is commonly used within qualitative research to organise and facilitate the coding of transcribed data. It is designed to support the use of coded data as labels to apply to data subsequently analysed such as in thematic or grounded theoretical approaches (Glaser & Strauss, 1967). In the present study, words, phrases and sections of text were coded by the specific effect the speaker achieved in a particular piece of talk. Annotations were used to detail those devices used to achieve this effect. Such coded effects were then collated to represent different interpretative repertoires they appeared to build within the interview.

### **Preliminary Characterisation of First Interviews**

#### ***Accounting styles***

Within the data from the 18 interviews analysed, five preliminary accounting styles were identified:

- *Compliance as passive:* The participant positioned her(him)self as engaged with their asthma, emphasising themselves as responsible and in control. There was a frequent use of the self-regulatory repertoire to position her(him)self against those who uncritically comply with medication instructions. This was an active rejection of compliance as an ideal. For example, the following participant constructed compliance to prophylactic medications as an act of uncritical and habitual dependence, positioning himself against “one of these people” who “rely” on medications and take it without question:

*I'm not one of these people who get up in the morning and think “right, inhaler, take it (.) before I go to bed, take it”. I don't want to rely on it like you know. Cos some people obviously will rely on their inhalers and they'll take it just because (1) it's their medication and I don't want to do that*  
(501441, interview 1, page 3, lines 6-13).

- *Minimisation repertoire using several rhetorical devices to justify medicine taking:* Participants with this accounting style either claimed that they did not have asthma, or that their condition was too mild to warrant adherence to prophylactic medication. Their own version of their condition was pivotal in justifying non-adherence to prophylactic medications, but did not blame healthcare for any misdiagnosis. In this following example, laziness operated as an acceptable device to justify non-adherence because it works to authenticate the speaker's (S) version of her asthma as something too mild to be taken seriously:

*S: well always, ever since I've had the inhalers, I've never done it properly.*  
*JM: why was that at the beginning then?*  
*S: lazy [laughs] I suppose because I don't have it badly enough. I would do it, lets put it this way, if I really suffered from asthma, and it affected my life, I would make sure I did it.*  
(530181, interview 1, page 3, lines 19-27)

- *Tension between lifeworld and medicine. Adherence potential threat to lifeworld:* Participants positioned prophylactic medicine taking as incompatible with activities in their everyday life. However, individuals with this style appeared to resist challenging the medical directive on adherence. In the following example, this

participant hinted at a tension between challenging clinical “experts” and his own preferred view:

*If its proved to be effective (.) and it is the considered opinion of the experts...was proved that this you know the preventative was instrumental in in you know (.) in in doing that or helping (.) helping relieve those symptoms then so be it if that's what it takes that's what it takes.*

(670287, interview 1, page 20, line 36 to page 21, line 5).

- *Blame of healthcare breaches sick role contract:* Participants blamed healthcare for not identifying the “real” cause of symptoms or for not communicating with them effectively regarding their condition and health generally. Taking prophylactic medications was therefore positioned as potentially treating the wrong condition. In the following extract, a key device in justifying non-adherence lay in this participant’s concept of the “root cause” of her breathing problems, which medicine was failing to address:

*What ... I am being sold at the moment is um something to keep me ticking over so that (3) I suppose so that I can breathe when I need to I I don't know how to put it really. It's not examining what the root cause...*

(351823, page 10, lines 39-43).

- *Minimisation repertoire using few rhetorical devices to justify medicine taking:* Participants with this accounting style did not enter into much of a dialogue about their asthma, appearing to have either nothing to justify, unwilling or unable to articulate an explanation for their medicine taking. Asthma was considered not to be a big issue in their life. These participants appeared to represent deviant cases because of the lack of a narrative about asthma and justification of medicine taking behaviour. The following example demonstrates a typical interactional sequence with the participant providing only short responses to questions regarding asthma management and medicine-use.

*JM: Yeah. How would you compare the tablets with the inhalers  
(3)*

*J: Al. Alri↑ght*

*JM: Do you think there's any differences?*

*J: Er (2) they don't seem to have no side effects or something (2) so long as I remember you know try to keep remembering to take one you have to to take one at night don't you*

(650405, interview 1, page 10, line 13-25)

Two participants were harder to categorise in these accounting styles. One participant constructed a pathological cause of their asthma management behaviour, positioning himself as passive and out of control. Problems experienced with asthma were blamed entirely on himself, *"I had asthma all my life and (.) still don't have it under control (1) which is down to me, you know really"* (660345, interview 1, page 2, lines 21-24).

Another participant, unlike the rest of the sample adopted a compliant position with prophylactic medications. Previous non-adherence was explained on being prescribed a prophylaxis with too low a dose, but in contrast to those who blamed healthcare, this participant praised doctors and nurses for the care he had received, *"Yeah that ((increased dose)) and the nurse yeah yeah it made one hell of a difference well I'm not blaming the doctor."* (261284, interview 1, page 3, lines 36-38).

### ***Interpretative Repertoires***

The interpretative repertoires that were identified within these accounting styles were designated as:

- *Self-regulatory*: Participants deploying this repertoire constructed themselves as active and engaged with their condition. The use of prophylactic medications was recognised as important but people who took them regularly were described as passive compliers.
- *Self-monitoring*: Participants using this repertoire could be seen to minimise the importance of asthma in their life and were reluctant to take prophylactic medications, preferring to respond to symptoms as necessary.
- *Self-blame*: This type of explanation involved acknowledging the importance of adherence to prophylactic medications and the role played by clinicians, then blaming oneself for not following medical advice.
- *Sick role*: Participants using this repertoire constructed a contractual relationship between themselves and clinicians. These explanations could be seen as versions

of Parson's sick role (1951), where patients should follow advice from a competent physician.

- *Root cause*: This type of explanation could be seen to be used by participants in conjunction with a sick role repertoire to argue that clinicians' failure to identify the real or "root cause" of their breathing problems represented a failure to fulfil the role of a competent physician.
- *Minimisation*: By minimising the importance of asthma in everyday life, this repertoire enabled participants to justify non-adherence to prophylactic medications. This could be seen either as constructing asthma as not real asthma or too mild to warrant regular preventive therapy.
- *Compliance*: This type of explanation could be seen as reproducing medical advice. This repertoire could be seen to be used within different interactional tasks, for example in conjunction with self-blame repertoire or as an indication of current medicine taking.

To illustrate the process of developing repertoires, extracts detailing effects and devices that constitute the self-regulatory repertoire can be seen in Appendix D.

### ***Methodological problems in the analytical construction of accounting styles***

Through attempting to identify the different ways participants accounted for their medicine taking, their "accounting style", a number of methodological problems were identified for interpreting the analysis of that data. These problems were related to the appropriate level of analysis required to examine interactional talk about medicine taking, the implications of this analysis for the ability to identify discursive variation in participant's talk and the appropriate method by which to validate findings from a discursive analysis of participant's talk.

*Level of analysis*: Setting an objective of identifying individual's accounting styles presupposed that the "individual" was the appropriate unit at which to conduct the analysis. The discursive psychological approach applied in this study viewed talk as language produced in a social space, situated in time and space. Viewing talk about medicine taking as connected to social historical contexts, entails adopting an analytical framework which can enable insight into those contexts which are activated in that talk. Viewing such talk only through the analytical lens of the individual however, limited



scope for a discursive analysis. This is because an individualistic focus has the potential to isolate that talk from these social conditions, so reducing interpretations to individual characteristics rather than reflecting the circulation and activation of different discourses in that talk.

*Discursive variation:* Adopting an individualistic focus also had implications for the types of insights that could be derived from such an analytical approach. These can be seen in the process of attempting to identify separate categorical accounting styles in the analysis. This process aimed to list “effects” and “interpretative repertoires” in participants’ talk with potential to generate thematic categories within the same interview or later, when interpreting further talk between participants. However, attempting this could also be seen to gloss over complexity and variation in the talk of participants. This can be seen in how interactional talk was de-contextualised so as to transfer it to the discrete categories of “effects” and “interpretative repertoires”, which were then to be used to develop the “accounting style.” In compartmentalising and abstracting individual utterances as accounting styles in this way, talk could be seen to be treated in a similar way to those individualistic approaches attempting to identify individual attitudes, potentially missing important variations in the functions of talk assigned to a particular accounting style.

*Validating analytical interpretations from first interviews:* Further problems were posed by attempting to provide an analytically sound basis for conducting a second interview with each participant. Second interviews were undertaken to validate interpretations of talk in the first interviews, and to identify persistence in moral discourses. Such a step did not fit logically with a discursive approach that treated talk as situated in interactional conditions.

It may be considered that by recreating the same interactional conditions in a second interview, participants could be seen to produce the same kind of talk on both occasions. Such similarity might be allowable when viewed from within a positivist paradigm, with similarities between the two occasions being seen as evidence that participant’s talk had persisted across two time points thereby strengthening claims that the same kind of talk might be found in a range of interactions. However, taking a discursive psychological perspective means that this talk must be examined in terms of its specificity to this interactional setting and not in the expectation that these data will

tell us anything new about how participants will talk in other interactions about their asthma. From a discursive perspective, identifying persistence therefore becomes problematic if data from two different circumstances are treated as representing talk from a broader range of interactions about illness management. Allowing for persistence within the same type of interaction does not fit with a discursive approach which, instead, will focus on how participants link medicine taking with morality under different interactional conditions, potentially enabling different discourses to be activated.

### *Resolving problems highlighted in analysing accounting styles*

The next phase of the analysis sought to resolve these methodological difficulties by adopting an entirely different analytical strategy to identify the role of moral discourses of asthma management and medicine taking in participants' talk. Rather than attempting to identify accounting styles through analytical review of those interviews, this alternative strategy, was to analyse full transcripts from face-to-face interviews so as to evidence morality in participants' talk. This reduced the extent of decontextualisation of talk from the context of research interviews. Whilst the production of "data", captured from an audio recording, can be seen as one form of decontextualisation (Burman, 2004) of talk, analysing transcribed talk nonetheless offered some opportunity to overcome the analytical problems of discursive variation identified. It also allowed an analysis of the process of production of meaning as something constructed between participants rather than derived from an individual, so resolving the problem of the individualistic focus apparent in the analysis of accounting styles. Finally, it enabled insight into what sorts of data would be required, to strengthen, or validate the author's interpretations about the role of morality that were made through the analytical process.

Adopting this alternative analytical strategy required decisions then to be made about how to treat the second interviews that had already been conducted with seven participants (reported in Chapter Three), and how to place the analytical concepts "accounting style" and "interpretative repertoire". The analytical focus had now shifted away from examining persistence in accounting styles across time points. From the discursive perspective now adopted, similar interactional conditions were being created in the second interview as in the first. It was therefore decided that the seven interviews

with participants who had previously been interviewed would be treated in the same way as first interviews and included as part of the main body of interview data.

The process of identifying “accounting styles” had shown to be useful for identifying a range of ways in which participant’s justified their asthma management and medicine taking and for substantiating the concept “interpretative repertoire”. However, because of the problems posed by individualising participants’ talk, the concept of “accounting style” was not deployed further as an analytical tool. However, the concept “interpretative repertoire” continued to be used to illustrate the variety of ways in which decisions about medicine taking could be seen to be explained by participants. Interpretative repertoires are produced interactionally to perform particular tasks. Unlike accounting styles, groups of people do not use some interpretative repertoires and not others. The same repertoires may be used by different people to perform very different functions. The “interpretative repertoire” was therefore a useful tool in helping to emphasise discursive variation in interactional talk, and so supporting a shift away from an individualistic focus on individual attitudes to talk about prophylactic medicine taking in multiple and dynamic moral discursive contexts.

### **Analysing Properties and Dilemmas in Talk about Prophylactic Medicine taking**

In this section, extracts from face-to-face interviews are examined, providing examples of some of the different ways in which moral discourses influenced the talk of participants. This is not to provide an exhaustive account of the many different ways in which people with asthma talk about asthma management. It will, however, demonstrate, through case examples, what can happen in talk about asthma management and medicine taking when public morality converged with personal experience in this research context. The presentation of this analysis will begin by showing how the properties of the discursive psychological approach adopted in this study could be seen as displayed in participants’ talk. These properties were seen in how: participants’ talk could be seen as situated social action; versions of events were authenticated and alternatives undermined using rhetorical devices which indicated a moral agenda for participants; talk was both constructed and constructive; and different types of talk may have operated simultaneously. These properties demonstrated the discursive dilemmas that participants faced within research interactions which were related to the allocation

of blame and accountability for participant's views and behaviour regarding medicine taking.

This analysis of how participants resolved interactional dilemmas revealed different moral positions that were activated through the ongoing discussion within face-to-face interviews. The analysis of talk about asthma management was therefore extended to engage with culturally-available moral discursive frameworks that could be seen to be activated within interactions. These discursive frameworks referred to moral discourses of illness management and medicine taking but also to other "lifeworld" (C. I. Salter, 2005; Schutz, 1962) discourses that may have interplayed with those specifically relating to the management of asthma. Talk was analysed to seek evidence of a discourse of accountability in participants' accounts which may have reflected the abstract discourses identified in asthma guidelines and other sources discussed in Chapter Two as well as other discourses that may have originated in different social spaces to the institutionalised medical discourses. Before examining the transcripts however, the process of transcription and analysis undertaken in this part of the analysis must be explained.

### **Process for Analysing Face-to-Face Interviews**

*Transcription:* The face-to-face interviews were captured on audiotape and then transcribed, based on a system developed set out in Atkinson and Drew's "Order in Court" (1979) which was based on Gail Jefferson's conversation analytic transcription conventions. Although many nuances of talk are lost in transcriptions, these conventions offered the best technique to facilitate an analysis of rhetorical devices as they enable as much of the detail of participant's talk as possible to be captured in written form, (see Appendix B for full details of conventions).

A first pass of the tape was taken to construct a loose transcription of the content of the interview. The tape was then listened to a second time to check choices in the transcript and to make further edits. This was originally done to incorporate as much of the detail of a sequence as the researcher could interpret as relevant. This included pauses below 1 second, changes in pitch and intonation, speech volume and the tempo of an utterance. This approach can be seen in interviews 670287 and 670289. However, having completed these transcripts, it became clear that the author selected sequences within

the transcript which related most closely to participant's asthma management. It was therefore decided that this level of transcription detail would only be undertaken when the researcher could identify relevance in a particular sequence for the participant's explanation of medicine taking. Details of transcription such as tempo and pitch were only included where the researcher noted them as helping interpret the turn-taking sequence between the researcher and participant or to interpret the rhetorical devices being deployed. For example, several participants told stories to justify their asthma management. In these cases it was considered that much of the detail of the story was the main focus of the analysis and key rhetorical device rather than how the speaker told the story. In contrast, where a participant seemed to be foregrounding a particular part of an explanation as critical in justifying their asthma management, then this was given emphasis in the transcript.

The transcript was then read through slowly, interesting phrases underlined and broken into sections if it seemed appropriate. When medicine taking, asthma management, or other health behaviour was discussed, an analysis of the rhetorical devices being used was undertaken. Other sequences which were also used as starting points were discussions of the participant's GP surgery and the NHS generally or views of health and illness.

*Analysis:* Appendix B sets out some key questions that were considered in analysing transcripts. Chapter Three proposed that the construction of objects of thought, otherwise referred to as "discursive objects", and interpretative repertoires are likely to be useful tools in analysing the accounts that participants provide, focusing on lexical features and grammatical styles used by speakers. In applying these tools a key requirement in providing a plausible interpretation of the data was to demonstrate "participant's orientation" (Potter & Wetherell, 1987, p. 170) to interactional issues. Speakers, in constructing rhetorical accounts, do not only deploy devices that will build a specific version of events but may also be seen to deploy devices that undermine alternative versions that pose a potential threat to how that person wants to be understood. Identifying participant's orientation to discursive issues meant pinpointing devices that address these threats to versions of the self, behaviour or "attitudes" towards a particular issue. This enabled participants' talk to be viewed from a moral framework where blame and accountability could be managed and allocated within interactions.

After analysing key sections in the transcript, the next step was to look for links and contrasts between analysed sections to examine whether similar positions were being constructed. This involved identifying important similarities or differences in the content and construction of talk. In addition sections not explicitly discussing asthma management were examined for any further insight into the interpretations formed thus far by the analyst. This then led to formulating the kinds of explanations that speakers appeared to be constructing at different points through the rhetorical devices they deployed. This part of the analysis developed the higher-order concept of the interpretative repertoire, as set out in Chapter Three (Potter & Wetherell, 1987).

The next stage involved specifying when the interviewee used a particular repertoire and not another which was used elsewhere. Repertoires may be used at different points for different reasons, may be multiple and contradictory. A key aspect of this part of the analysis involved looking for whether different repertoires created new problems for the speaker. Wetherell has suggested that a key way to validate the identification of repertoires is to examine if a particular combination of repertoires creates “trouble” for the speaker, (M. Wetherell, personal communication, February 2, 2006). We saw in Chapter Two how the nurses in the research of Jones et al (2000) on asthma self-management plans appeared to manage such a tension between notions of autonomy and accountability, by constructing a contingent version of the nurses’ role in their patient’s asthma. Their orientation and management of these tensions provided evidence that they were drawing on a moral discourse of asthma management also identified within asthma guidelines. The analysis by Gilbert and Mulkay (1984) of scientific talk provides another example as seen in Chapter One. They identified a “truth will out device” (Potter & Wetherell, 1987, p.153) was being used in scientist’s talk to manage potential accusations of bias that seemed to emerge as an issue in their talk, when discussing the differences between their own work as “empirical” and other scientist’s work as “contingent.” Identifying these devices therefore provides a form of validation for the analysis and enhances the trustworthiness of an analytical interpretation (Potter & Wetherell, 1987). However, such devices may be difficult to identify and caution is needed when interpreting tensions and contradictions in a participant’s talk. What may appear as a contradiction may have some supportive causal link which made sense in the context of the interview. In analysing discursive tension the issue was to examine

whether the sequences of talk were closely linked in the interview and whether the person could be seen to actively manage any such contradiction.

Finally, having provided evidence that interviewees were engaged in a moral agenda to justify their asthma management and medicine taking, the data were analysed to see whether links could be made to different moral discourses that circulate society regarding asthma and illness management. These could be the moral discourses discussed in Chapter Two around appropriate illness management as seen from the asthma guidelines, older discourses of asthma and emotional control, contemporary notions of illness prevention or those relating to symptom control as seen in the latter half of the twentieth century. Alternatively other discourses may have been activated which may have contributed something new to those already identified. To make these links, the interpretative repertoires that participants deployed were re-examined for evidence that these repertoires could be interpreted as versions of moral discourses of illness management or of other discourses that may influence an evaluation of the speaker's asthma-related behaviour. As illustrated in the analysis of data provided in the study by Jones et al, the technique for doing this lies in how rhetorical devices, such as discursive objects, function to construct repertoires that appear as versions of culturally-shared moral discourses.

The analysis presented in this chapter will therefore set out and identify key sections of face-to-face interviews which appear to show participant's orienting to competing versions of their medicine taking behaviour. These examples will be used to make links with the moral discourses of asthma and illness management and medicine taking described in Chapter Two so as to provide a basis for a discussion of the implications of morality in talk about prophylactic medicine taking in Chapter Seven.

### **Analysis of Interview Transcripts**

To demonstrate the discursive properties within participants' talk, extracts from four face-to-face interviews are presented here as case examples and then analysed in depth. They were chosen as they display very different ways in which participants could be seen to justify their medicine taking, and were each deliberately selected from different accounting styles identified in the early analysis. Despite being assigned very different accounting styles, these participants can be seen to have distinct similarities in the

interpretative repertoires that they deployed and the moral discourses of medicine taking that were activated within those interactions. By identifying what is different and what is shared in these interactional sequences we will be able to demonstrate the analytical problems in identifying accounting styles, how these have been resolved in a detailed analysis of transcripts, examine the relationship between discourses of morality and individual utterances and highlight what can be gained by taking a discursive psychological approach to this problem. The face-to-face interview dataset collected in this study therefore represents a range of ways in which talk about medicine taking may be manifested within a particular type of interaction. By drawing links to wider cultural discourses, it aims to illustrate the circulation and activation of morality within this interactional context which might indicate the importance of considering the influence of morality in talk about medicine taking more generally.

Excerpts from transcripts from the four interviews reported in this chapter can be found in Appendix B. Each excerpt includes at least one of the extracts reported in this chapter and enable the author's choice of extracts to be examined and facilitate further insight of how participant's versions were sequentially constructed within the interactions taking place. In addition, full transcripts of all interviews cited within the main text of this thesis have been provided in a CD as an appendix. Pseudonyms have been used in all extracts presented here. The line numbers quoted in the title of each extract correspond to the line numbers of the excerpt included in the appendices. However, the line numbers used in presenting this analysis correspond to the numbers used in the extracts.

### **Constructing “Non-Adherence” using Scientific and Psychological Repertoires**

Extract One is taken from a second interview with Dave. Dave was aged 39, had asthma all his life and lived in a detached house in a rural location. He stated that he was a manager of a car showroom or company, a Chelsea football supporter, golfer, keen gardener, visited his local pub regularly where he met with friends and had talked about asthma. He also stated that he was financially well-off, went on holiday three times a year and had left a large sum of money to asthma research in his will.

“I have my solicitor raising his eyebrows when he saw how much money I left asthma research in my will” (page 30, line 51 to page 31, line 1). Dave was prescribed an asthma prophylactic tablet which was supposed to be taken once a day to be effective. This treatment replaced the brown inhaler which he was prescribed prior to participation



in the ELEVATE study. In the analysis of first interviews, Dave was categorised as having accounting style 1 - *Compliance as passive*. In Extract One, we can see an example of how Dave justified not taking the prophylactic brown inhaler by deploying two repertoires. Early on in this extract we can see a scientific, rational repertoire. This has similarities with the “empiricist” repertoire identified by Gilbert and Mulkay, reviewed in Chapter One. Then we can see a psychological repertoire.

***Extract One: Participant 500367 (Dave). Interview 2, page 5, line 1 to page 6, line 51***

1. JM: (1) So what, what are the differences do you think, or the relative  
2. difference between (1) eh, tablets and the brown inhaler?
3. D: (3) I think it's, I think there's an element of psychology comes into it.  
4. (1) And I think there's a degree of psychology comes into everything  
5. (1) in as much as (.) partly because I think those tablets are doing some  
6. good (.) it's certainly got to help the job a lot (1) help the fact that they  
7. are.
8. JM: Yeah.
9. D: (2) Em, (1) the brown one I'm absolutely, I've managed to convince  
10. myself beyond a reasonable doubt, it doesn't work or its effects are (.)  
11. minimum, minimum effectiveness. (2) I know, I, I've had (1) asthma  
12. (1) all my life. I've you know, I started with the little pink tablet but  
13. through to the Ventolin, then went on to the big white ones which were  
14. foul, before that we had spin halers and all these thing we used to have  
15. to put out fucking cups in and things and cracking and things. I've  
16. been through the full nine yards with this. (1) As soon as Ventolin  
17. appeared (1) instantly you have something which is a cure (1) (??).  
18. You went from having (1) asthma (1) to using it (.) to being perfectly  
19. normal again (1), like that. (1) It was (2) a big, big difference. (5) The  
20. brown, I mean with, I've had two or three or four different doses of the  
21. brown one and I've played about with it for (1) a week, for (.) nine  
22. months sort of thing, and I'm adamant that it's not made any  
23. difference. (3) It really hasn't. (1) Yeah and I did forget to take it and I  
24. did forget to, it was just (.) h, how (4) and the, this thing about using  
25. the two in conjunction. (1) Well, (2) it just, I just never (1) really  
26. accepted it.

27 . JM: (1) So is it, is it just the eh (3) the drug itself or is it the device that,  
28 . that's in it as well [is there anything else about]  
29 . D: [Oh no, I don't think] there's anything (??). No.  
30 . JM: It's not like I  
31 . D: (3) I, (2) it's, it's, I, I have experimented with it and, and you know a  
32 . week playing with it and then a week without it and then a week with it  
33 . and I really can't tell you that there, that there was a great deal of  
34 . difference among any.  
35 . JM: Right  
36 . D: There really was none (?) (2). I've been better with these tablets in as  
37 . much as I know for a fact that I have ordered less Ventolin (.) since I've  
38 . been using those than I was before.  
39 . JM: (1) Do you think you've eh, (1) taken (.) the tablet more regularly?  
40 . D: I've taken the tablet, yeah.  
41 . JM: Right.  
42 . D: Oh definitely, definitely (2).  
43 . JM: What would you say about the (2) given what you've said about  
44 . psychology (2) what you know about it and the fact that you definitely  
45 . taken them (??) more regularly (1) what do you think the possible  
46 . differences in treatments?  
47 . D: Going back to what I said at the beginning (1) I think there's an  
48 . element of psychology in as much as (.) because I'm (1) pretty  
49 . adamant I've been told that this will (1) help effectively but, (.) I've  
50 . been taking it, I've been going along with it, I've certainly as I said,  
51 . used less Ventolin at the same time (2). No, no problem at all. (1)  
52 . Brown one was very hit and miss in as much as I would forget to take  
53 . it didn't matter where I put the thing. (2) I had them scattered, I had  
54 . one in the car, one in the, beside my bed, one in my office and I'd still  
55 . forget to take it. (1) I don't know why but I just did.  
56 . JM: (3) That's interesting.  
57 . D: (2) I think it was, I think it was (1) the fact that (1) it, it's so similar to  
58 . the original (.) the blue one, the Ventolin (.). That (1) you use when  
59 . you've got asthma, when you're having an asthma attack or (??), you  
60 . use the (??) (1) and it's (1) that's a cure, you pick it up, you reach for it  
61 . at that point (2) to (1) go to the action of using exactly the same sort of

62. (1) when there's nothing wrong with you, is not a natural (2), and I  
63. think there is an element of that feeling.

A key way in which Dave explained his use of prophylactic medications and which is evident in this sequence is through his use of a scientific repertoire. He constructed his argument using legal and scientific terminology “beyond a reasonable doubt” (line 10), “minimum effectiveness” (line 11), combined with an empirical approach to test out the brown inhaler (lines 31 to 34). This active construction juxtaposes with a sense of passivity with the types of medication provided, a dependency with what has been available at different times, emphasised with a sense of frustration in lines 15 to 16. This mixture of articulating objectivity alongside subjective, long-term experience, “I know, I’ve had asthma all my life” (lines 11 to 12), displayed a powerful piece of rhetoric for demonstrating that his account of the effectiveness of the brown inhaler medication was the authoritative one. The effect was to construct his asthma management and himself as well-intentioned, rational and reasonable, but thwarted by inadequate treatments. Not only this, but he was not someone who just accepted the advice he was given, but someone who made his own mind up, “I’ve managed to convince myself beyond any reasonable doubt” (lines 9 to 10). This is a direct rejection of the notion that patients should passively comply with instructions to take medications as prescribed, instead asserting active monitoring of the medication’s effects. His “non-adherence”, within this repertoire that Dave constructed is perfectly plausible in the context of recounting the work he had done himself to test out the effectiveness of brown inhalers.

However, Extract One also demonstrates Dave using a psychological repertoire to account for his non-adherence to the brown inhaler. Dave discussed different elements of psychology including forgetting, visual association with blue inhalers (lines 57 to 63), notions of psychological acceptance, “I just never really accepted it” (lines 25 to 26), the placebo effect (lines 4 to 7) and the psychological impact that the introduction of Ventolin as a new treatment had in the management of asthma. The detail provided in his endeavour to overcome his poor memory and take the brown inhaler regularly, in lines 52 to 55, suggests Dave was attempting to discredit any notion that he did not try hard enough with the brown inhaler. As already identified by Cornwell (1984) and more recently Radley and Billig (1996), notions of being in work, or a hard worker, are often linked to undermining potential accusations of being a malingerer. Dave, using a

metaphorical “scattering” of inhalers in key locations, constructed a version of himself as someone who is in many places on a daily basis, of which his office is one. Forgetting to look after his health is set within this context and the “scattering” strategy is therefore represented as a proactive attempt to overcome the limitations of his own psychology brought about by this busy lifestyle. Dave’s non-adherence was set within a broader cultural discourse of the busy working individual and importantly not within a context where remembering things might be seen as not a problem. This rhetorical work therefore undermined potential criticism that Dave was lazy in his attempts to adhere to the medication. As well as using the scientific repertoire in this extract, Dave also undermined any suggestion that he had an irrational and incorrect perception of his medications. This was achieved by constructing himself as committed to seeking out the truth through endeavour, objective empiricism and experience, three attributes that can be widely seen as core values in a working context.

An important device Dave used when deploying the psychological repertoire was the construction of the brown inhaler as something that wasn’t “natural” to use “when there’s nothing wrong with you” (line 62). From a social cognitive perspective, this type of statement has been repeatedly identified and categorised as an individual attitude where the individual does not view their asthma as a long-term condition (Halm et al., 2006; Horne & Weinman, 2002). However, Dave clearly demonstrated in this extract that asthma was something he had lived with all his life, repeatedly confronted and, with his regular taking of the tablet prophylaxis, that he fully understood the function of prophylactic medications in that his adherence to the tablet had resulted in Ventolin being required on fewer occasions. By viewing Dave’s talk from a discursive perspective, his statement about the brown inhaler was contextualised in a version of Dave as the informed scientist and not someone who has incorrect beliefs.

***Blame, accountability and moral discourses in Extract One:***

By deploying a scientific and psychological repertoire, Dave could be seen to have been simultaneously active and passive in accounting for his medicine taking behaviour and both repertoires could be seen to have worked in tandem to manage potential accusations that he was not managing his asthma appropriately. This was achieved by demonstrating the steps he had actively taken to take control of his asthma whilst also demonstrating the limits to his own agency in asthma management. This was shown

initially in expressing his frustration at having to follow strange and ever-changing regimens that had not, until the advent of Ventolin, provided the level of control he had sought; and then with unconscious aspects of individual psychology limiting his ability to remember to adhere (set within a context of being a busy working individual) and to “naturalise” and “accept” the brown inhaler as a creditable treatment for his asthma. Seen in this way, Dave’s symptoms were as a result of understandable and acceptable limiting circumstances, and not due to personal laziness or any “irrational” rejection of the value of medications, or denial of his condition.

This analysis indicates that a moral discourse of asthma management was activated in these interactional sequences which can be seen to orientate around Dave constructing a version of the virtuous ill person. This was someone who made an active attempt to control their condition in difficult circumstances, not merely accepting the advice they were given. This is not a traditional medical idea of the ideal patient but is a reconstruction of more contemporary notions of the “asthma expert” seen within recent patient-centred initiatives, (Department of Health, 2001; Taylor & Bury, 2007) but also within wider ideologies of twenty first century working life and of the “reflexive consumer.” By positioning himself on the positive end of this moral dimension of illness behaviour, Dave provides plausible explanations for his medicine taking behaviour, problems with asthma control and control of his asthma management and health more generally. Importantly, rather than viewing statements about his individual psychology in isolation, as a social cognitive perspective might do, the interpretative repertoires that Dave uses in this sequence are interdependent and lead to a different interpretation when seen together.

### **Deploying a Sick Role Repertoire to Blame Healthcare**

In contrast to Dave’s stance, Extract Two is taken from a second interview with Irene, who can be seen to have taken up a more passive and fatalistic stance towards the healthcare she received. Irene was classified in her first interview as having accounting style 4 - *Blame of healthcare breaches sick role contract*. Irene was 63 years old but was 48 years old when she had been diagnosed with asthma. In this extract, Irene was explaining why she didn’t like taking tablets. She was prescribed an asthma prophylactic tablet as part of the main asthma trial and argued here that she stopped, as she thought they made little difference to her asthma.

*Extract Two: 121221 (Irene). Interview 2, page 3, line 11 to page 4, line 2*

1. JM: yeah, so you, when you entered the study and you were prescribed the  
2. tablet.
3. I: Mmmm.
4. JM: You said you stopped taking it two or three months ago, were you  
5. taking it every day or?
6. I: I took it every night. I had it up beside my bed, but what actually  
7. happened I lapsed (1) eh, over Christmas time (.) I didn't get one in  
8. because I didn't order it in time (1) and then I went without and then I  
9. just sort of (1) left it you know?
10. JM: (2) You said you didn't notice any difference?
11. I: I haven't noticed any difference because (1) I still had the attacks (1)  
12. you know, (1) but em, (2) as I said I've also got another one I take for  
13. (2) eh, (?). (2) Arthritis (1) now I don't like that tablet at all (1) I, and  
14. I don't even think that works either (1) [and actually]
15. JM: [What don't] you like about them?
16. I: Pardon?
17. JM: What don't you like about the tablets?
18. I: (1) I think you keep filling your body up with all these tablets and (1)  
19. you know (3), I don't know I just feel that, is that causing my problem  
20. (2), you see with my problem (1) my stomach problem (1) I just, I (??)  
21. with my stomach. (2) em, (1) I feel everything I eat (1) I get pain in  
22. here I ain't been to the doctors with it yet (1). Sort of there like, I don't  
23. know if I got an ulcer or what (.) and I, I think tablets (2) you know,  
24. (1) I don't know it might be me, I ain't really a (1) big fan of tablets.  
25. (1) You see but I have been taking them for years (1) coproximol and  
26. I'm saying years, no they're now telling you (1) that they're bad. (1)  
27. They going to take them off the shelf, don't know if you saw the  
28. article?

Irene, like Dave, reported that she did not notice any difference in her symptoms after taking a prophylactic treatment regularly, although with Irene this was the tablet form rather than the brown inhaler. Like Dave, this perceived failure to change her symptoms

formed the main basis of the argument for not continuing with the treatment on a daily basis. Irene also reported forgetting to take prophylactic medications used for the prevention of symptoms, “I lapsed” (line 7). However, we can see that Irene’s statement of forgetting had a very different effect within the interaction than that of Dave. Dave reported forgetting but only in the context of also demonstrating how active he was in managing his asthma, how many steps he took to prevent himself forgetting and that his good intentions were thwarted by unconscious psychological forces. Here, Irene showed how she managed to take the treatment regularly by keeping the tablets at her bedside, but this only preceded a simple statement that she “didn’t order it in time (1) and then I went without and then I just sort of (1) left it you know?” (line 9). In contrast to Dave, there was little rhetorical work done by Irene to justify this forgetting and in this sequence, non-adherence to the asthma medication did not appear to be a major concern. Instead of forgetting being set within a context of active engagement with asthma, the effect of Irene’s talk is open for interpretation, one of which could be that she had “given up” or “misunderstood” the function of the medication and her asthma.

Following the interaction further however, we can see that Irene provided a broader concern about tablets which served to contextualise the decisions about the asthma tablet. “I think you keep filling your body up with all these tablets” (line 18). Irene used a powerful metaphor to directly challenge the value of taking an aggregated category “tablets.” The idea of the body as a container which can be filled up stressed the argument that adherence meant her body can’t keep anymore tablets in, spilling over with medication. She blended mitigating phrases “I don’t know I just feel that” and “I don’t know it might be me” with a personal narrative of her long experience with tablets and current stomach problems to present her criticism of tablets. The sense of apprehension, emphasised with a lack of cohesion in the sentence “(1) I just, I (??) with my stomach. (2) em, (1) I feel everything I eat (1) I get pain...” (lines 20-21) suggested an uncertainty in presenting this position, yet her arguments were supported and therefore normalised with reference to a press article as evidence “they’re now telling you (1) that they’re bad” (line 26). By using the collective term “they” to refer to scientists and medicine, Irene might have been justifying not using the tablet therapy for the prevention of asthma by associating it with and undermining the solidity of medical knowledge regarding another tablet. Her behaviour could then be accepted as reasonable because if the medical knowledge about medications changes then it cannot be trusted, raising questions for taking them. Her earlier statement that she “just sort of left it” (line

9), could then be understood as acceptable and freeing her from blame for not taking the asthma prophylaxis as prescribed.

As this sequence in the interaction continued, Irene's position on medications was set further within dissatisfaction with healthcare more generally. Again we can see similar rhetorical devices were being used by Irene to account for her (lack of) attendance at her local surgery.

***Extract Three: 121221 (Irene). Interview 2, page 6, line 38 to page 7, line 7***

1. JM: So you've been (1), how many times have you been back in to the
2. surgery in the last year? [for your asthma?]
3. I: [I'm a], you see this is the thing (1)
4. I should see an asthma nurse but thing is (.) the only time my asthma's
5. ever mentioned (1) down that surgery (1) is if I had, like when I had
6. bronchitis (1), "ooh, you got asthma (1) eh, take (1) more (1) inhaler"
7. you know, "do more(.) inhaler" (1) but apart from that there's no (1)
8. em, (1) request to see the asthma nurse or anything like that, (1) and as
9. far as "I'll be honest with you (1) I do find in today's world (1), and
10. I'm not alone (1) we got one of the best surgeries I think down there, I
11. really do (1) but, (.) they still like say you went down with a complaint
12. (2) and you got two or three other things on your mind (1), they don't
13. want to hear, you got to make another appointment all the time. (1) For
14. the specialised thing, whatever you want (1) and invariably I think they
15. don't really (2) you know, want to know really to be honest."

In this extract, the interviewer's (JM) question appeared to represent a face-threatening act which Irene could be seen to orientate towards. The issue appeared to be the possible criticism that she was not taking responsibility for her asthma because she had not attended the surgery as often as she should. This concern is first evidenced with the use of the modal verb "should" (line 4). However, this was merely a preface to direct criticism of the quality of care that she had received, namely that the surgery did not take enough of an interest in her asthma, "the only time my asthma's ever mentioned (1) down that surgery" (lines 4-5) and that "they don't really (2) you know, want to know really to be honest." (lines 14-15). Irene constructed a very clear picture of herself on



the one hand - as a patient with concerns she wanted to discuss, and “that surgery” on the other - as dismissive of these concerns and lacking interest in her individual circumstances. These versions were not merely described however, but were authenticated using a range of rhetorical devices. First of all, she provided a specific example to script a typical response to her expressions of concerns about her asthma, adopting the voice of doctors and nurses in an ironic tone “ooh, you got asthma (1) eh, take (1) more (1) inhaler” you know, “do more(.) inhaler” (lines 6-7). This was followed by a normalisation device, positioning her uncaring surgery as pervasive of the NHS more generally and representative of an uncaring world. Moreover she used the evidence of allies in her viewpoint “I do find in today’s world (1), and I’m not alone” (lines 9-10). This served to rationalise her argument by erasing any notion that this view was radical or an irrational judgement of her local surgery. She also added further weight to her argument by twice revealing that she was confiding in the interviewer – “I’ll be honest with you...to be honest.” This is a truth claim, something which has been thought through already and to which she has amassed evidence to support. Irene, also set these criticisms within a mitigating phrase which served to position her criticisms as reasonable, “we got one of the best surgeries I think down there, I really do” (lines 10-11).

***Blame, accountability and moral discourses in Extracts Two and Three:***

Like Dave, Irene could be seen to manage issues of blame and accountability for her decisions and views about medications and healthcare generally. In doing so, a moral discourse of illness management and health behaviour appeared to be activated within the interaction which Irene deployed in allocating who was to blame for her symptoms and decisions about medicine taking. In both extracts taken from the transcript of Irene’s interview, we are left in no doubt that Irene made a particular connection between the provision of health and a particular moral expectation. In Extract Two, the expectation was that the treatments provided should meet their intended purpose, that those who prescribe it do so with a commitment to making the patient better, and therefore not with detrimental side-effects. In Extract Three, Irene set up a moral connection between those who provide healthcare, how that care should be delivered and the motivations and characteristics of those doing the caring.

It may be interpreted that Irene was deploying a “sick-role repertoire”, drawing on a Parsonian sick role discourse (Parsons, 1951) commonly understood in British society. The principles of Parson’s sick role that have traditionally been associated with the doctor-patient relationship are that illness is a form of social deviance in which an individual adopts a certain role. The sick person is exempted from normal social responsibilities, is not blamed for being sick, is expected to seek competent help in the form of a doctor and is expected to comply with the regimen prescribed by a competent physician. The interpretative repertoire that Irene deployed was not an exact replica of Parson’s concept but instead drew on this traditional model of the doctor-patient relationship, which is circulated through British society, to construct a version which tackled the particular issues at stake within the interaction. These issues appeared to orientate around whether Irene was or was not appropriately managing her asthma, whether she was justified in not attending her surgery more frequently and whether her decision to not take prophylactic asthma medication was an acceptable one. Irene’s version of the sick-role included criteria for a competent physician - somebody who attends to each patient’s individual circumstances, “the specialised thing” (line 14), and one which should be proactive in the management of patient’s asthma (lines 7-8). Her sick role repertoire also included images of medications and the people who take them. In deploying a visual metaphor of the individual passively filling up and spilling over with tablets (Extract Two, line 18), she activated a culturally-available conceptualisation of the sick individual with a range of unspecified symptoms and vague causes of which the tablets were producing rather than solving. By constructing the sick-role in this way Irene was able to justify not only her non-attendance but also her decision to not take the prophylactic asthma tablet, which was positioned as virtuous and preventive rather than causative of illness.

Irene’s approximation of the widely understood sick-role discourse enabled herself, medications, doctors and nurses, to be positioned within that discourse, according to her personal experiences and circumstances, and assigned a moral value to the different participants set up within that discourse. Irene’s justification of her decisions about her asthma and medicine taking rested on the argument that doctors, nurses and the institution of medicine had not met the conditions of competent physician and reliable treatment regimen. Irene’s criteria of the (de)-personalised doctor-patient relationship and visual imagery of the passive patient spilling over with medication detailed the evidence of how this condition had not been met. In this sense, the institution of

medicine can be said to have violated the sick-role contract that Irene had set up within this interaction.

### **Deploying a Sick Role Repertoire for Self Blame**

In the case of Irene we saw how her explanation for asthma symptoms and other health problems were managed by directing blame towards the dangers of medications, the lack of certainty in the knowledge of the medical profession as well as directly questioning the motivations of clinicians themselves. This strategy was identified in several participant's accounts (e.g. see full transcripts on CD for 261906; 141693; 351823). In contrast, Stephen was the only participant who repeatedly blamed himself for his problems with asthma.

In the lead up to Extract Four, near the end of this interview, Stephen had been asked how he saw the future in terms of his asthma management and also to reflect on his experiences with doctors and nurses. Here we can see how Stephen directly positioned himself as a bad patient within a moral framework of a sick role discourse.

#### ***Extract Four: 660345 (Stephen). Interview 1, page 23, lines 41-45***

1. S: I don't have any complaints (2) over (1) my treatment of doctors or
2. asthma nurses over the last few years. I think basically they've been
3. banging their head against a brick wall with me over the years (1).

Here, Stephen used a common metaphor of banging one's head against a brick wall to describe GPs' and nurses' roles in helping him. This positioned clinicians as persistent and well-intentioned and importantly active in doing the "banging." In contrast, Stephen was constructed as the wall - a fixed, immovable object. Having "no complaints" therefore set this metaphor within a moral discourse of roles and responsibilities which clinicians were fulfilling. Again, like Irene, Stephen was deploying a sick role repertoire which set up a contract between him and the doctors and nurses. The issue then was how Stephen positioned himself within this discursive moral contract and in Extract Five, Stephen seems to be summarising how he wished to be understood within this moral context. In contrast to Irene, it was Stephen who was violating the sick role contract.

***Extract Five: 660345 (Stephen). Interview 1, page 27, lines 33-41***

1. JM: Is there anything you feel you haven't said? (1) Or anything you want
2. to ask me?
3. S: I'm just sort of glad to be part of this study and (2) in a way feel
4. guilty (1) on my part over (2) the years of not (1) being very helpful or
5. (1) cooperative or whatever hhh and I just think well if I've got a
6. chance...

However, Stephen did not only admit guilt but he also displayed remorse for his behaviour and then offered a commitment to become a better person given a chance. We can view these notions of guilt, cooperation and having chances as reproducing a rehabilitation discourse which is not only set within a dominant medical discourse of remission (Frank, 1995) but can also be seen in wider society in reference to the probationary discourse of criminals (Proeve, Smith, & Niblo, 1999). Stephen's justification of non-adherence, which these examples demonstrate, orientated around constructing himself at a crossroads in his life. Within the sick role discourse that was activated in this interaction, Stephen could be seen morally to be taking the right road at this crossroads. Whilst his previous behaviour was positioned as uncooperative and as a violation of a sick role contract, the commitment to change, functioned interactively to present himself as on a different road, as a purposeful and rehabilitated patient. However, this talk of self-blame and rehabilitation was also set within a psychological repertoire which resonated with Dave's account. Like Dave, Stephen constructed notions of an unconscious psychology influencing the management of his asthma, seen in Extracts Six to Eight.

***Extract Six: 660345 (Stephen). Interview 1, page 18, lines 19-26***

1. S: It's sort of been a pattern of (.) not having many symptoms and not
2. having any preventative or reliever (1) or very little reliever (1) and then
3. (1) when the times come when I'm not well or seasonally in summer (1)
4. I have (3) still no preventative medicine. Go and get prescribed it (.)
5. from the doctor (.) knowing full well that I'm not going to take it (1). I
6. don't know why.

***Extract Seven: 660345 (Stephen). Interview 1, page 23, line 52, to page 24, line 8***

1. S: it's been myself that's been (2), not unwilling I wouldn't say but just (2),
2. °“ah it's alright”° you know just (.) carry on (1) really (2), °just carry on
3. with it° (1) You know? “I haven't, I'm not wheezy so, (2) you know I'm
4. alright.” (1) And it's sort of that sort of mentality really (1). Sort of
5. accepted that I've got asthma and eh (3) at times “I'm not wheezy (2)
6. °I'm fine” (1) you know?°

***Extract Eight: 660345 (Stephen). Interview 1, page 11, lines 12-22***

1. S: Em, (1) if you haven't got the Ventolin at hand (1) then you can sort of
2. get panicky, do you know what I mean?
3. JM: Yeah.
4. S: If for example, it's getting low or (1) you've left it somewhere else,
5. you know you're out and you haven't got it (1) or, you know, if it's not
6. at hand basically (1) it's (2) there's a sort of (1) panic, as such.

***Blame, accountability and moral discourses in Extracts Four to Eight:***

In contrast to Dave, but similarly to Irene, Stephen drew on traditional ideas of the doctor-patient relationship and constructed versions of himself, doctors and nurses in explaining his non-adherence to medications. However, unlike Irene, Stephen undertook little rhetorical work to discredit potential alternative interpretations of his actions. This was most likely because he blamed himself for his non-adherence and positioned his explanation within broader discourses of remission, rehabilitation and remorse. Blaming oneself and not doctors offers a submissive and compliant position within traditional doctor-patient conceptualisations. This discursive action does not challenge a powerful institutionalised set of roles and relationships but instead reproduces a widely understood discursive object, the “bad patient” within this common discourse. In addition, in British society an explanation of self-blame and remorse is typically viewed as “honest” when activated within a rehabilitation discourse. There was therefore little need for Stephen to provide supporting evidence for the version being constructed. A slightly different interpretation to this might be that we can view Stephen's admission of

guilt as his attempt to save “face” within the interaction taking place. Criticising himself arguably enabled Stephen to “own” any judgement of his behaviour, rather than potentially having it directed at him through the ongoing discussion. Stephen’s “owning” of the criticism may therefore have limited the need for Stephen to justify his asthma management any further.

This contrast between Stephen and Irene’s accounts, in how the sick role discourse was deployed, provided an important point of triangulation between the two forms of justification. This was that the construction of the “bad patient” within Stephen’s sick role discourse, (requiring little rhetorical work and supporting evidence), and the “bad doctor” within Irene’s account, (requiring a lot of rhetorical work and supporting evidence), highlighted the moral value attributed to being a compliant patient within a medical discourse regarding clinical advice and prescription instructions. As Chomsky argued, when discussing structural constraints within mainstream media on the production of unconventional thought: “The beauty of concision...is that you can only repeat conventional thoughts.” (Achbar & Wintonick, 2009). This point of contrast between the interviews of Irene and Stephen therefore provided further evidence that a moral discourse of illness management was activated within participants’ talk which included traditional notions of compliance to doctors’ instructions.

In contrast to Dave’s use of a psychological repertoire which functioned to justify non-adherence within a busy lifestyle, Stephen constructed a version of his psychology which appeared to reinforce his discussion elsewhere that he was to blame, (set within a sick role repertoire), for his poor asthma management. In Extract Six, Stephen constructed himself as at the mercy of unconscious forces and pathologised his behaviour “Go and get prescribed it (.) from the doctor (.) knowing full well that I’m not going to take it (1). I don’t know why.” (Extract Six, lines 4-5). In Extract Seven by contrast, it was a symptom control “mentality” that was normalised, which prevented him from taking prophylactic medications. Finally, in Extract Eight, his relationship with asthma relief medication was constructed as psychologically dependent, leading to panic if the inhaler was “not at hand.”

The psychological repertoire that Stephen deployed resonates with the discourses of control identified in Chapter Two. The notion that Stephen’s medicine taking behaviour was driven by something he was unaware of reflects 1950s psychoanalytical

connections between unconscious, repressed emotions and the manifestation of asthma symptoms and asthma-related behaviour (Alexander, 1952; Dunbar, 1947); while the links he made between panic, relief medication and asthma attacks echoed theories constructing the converse relationship between emotional control and the symptoms of asthma (Wright et al., 1998). These connections were identified elsewhere in the sample (participant 261906, pages 4-5; 670217, page 2). However, there was little evidence in the analysis that these participants were directly orientating to or had access to these specific discourses and the connections made here are the interpretations of the researcher. As discussed in Chapter Two, notions of self-control (Williams, 1993, pp. 92-108) have circulated British society in a range of contexts and talk such as Stephen's may have origins within broader moral discourses of embodied control in lifeworld settings. In contrast, there was stronger evidence that a "symptom control" discourse was activated within Stephen's psychological repertoire, which could also be seen to be used by Dave as well as other participants in the study. Non-adherence to prophylactic medications was frequently explained in the context of forgetting, a "mentality", or in terms of responding to symptoms, despite these participants displaying a clear understanding of the function and need to take prophylactic medication regularly. We saw earlier how Dave situated his forgetting within a busy working context. A key device in presenting forgetting as a justification for non-adherence, which participants such as Dave and Stephen shared, was to present this explanation in the context of a willingness and intention to comply. In Stephen's case this was clearly stated: "not unwilling I wouldn't say but just (2), °'ah it's alright.'°" This indicated that a "symptom control" discourse was perhaps widely circulated at the time of interviewing participants and that this form of explanation was considered acceptable and more compatible with participant's everyday lives than a discourse of asthma prevention.

However, it is possible to see how Dave's and Stephen's use of symptom control explanations have the potential to be judged differently, depending on how their different justifications are positioned within different moral frameworks that were activated within interactions. Dave's "scattering" of relief medication in a variety of locations, (line 53) was functionally plausible when set within a discursive framework of active engagement and management of one's health. Actively taking control of one's body is potentially a powerful explanation within medical and lifeworld moral discourses of illness management and also broader discourses of individual responsibility. Dave also positioned himself as someone who donated money to asthma

charities and as someone well-informed about asthma and experienced in the different treatments that had been available. Responding to symptoms, rather than preventing them was therefore constructed by Dave as responsible and morally acceptable when positioning himself within a discourse of the active manager and contributor of society. Contrast this explanation with Stephen's account of a similar kind of behaviour. Stephen positioned his behaviour within a sick-role discourse where the advice had been to take his prophylactic medication regularly. Managing asthma through symptom control rather than prevention was therefore constructed as irresponsible and it was Stephen who was to blame for poor asthma outcomes.

Both Dave and Stephen's explanations "made sense" within these discourses, at the time the interaction took place, yet despite similar behaviours, blame and accountability were distributed differently. Blame and accountability are therefore apportioned according to the individual's constructed position within the moral discourses that are activated within interactions. However, different moral discourses may function more effectively than others at different points in time and within different interactions. From a clinical perspective it is conceivable that explanations such as Dave's could be seen as inadequate and irresponsible within a moral discourse of asthma management that puts prophylactic medications at the heart of that discourse. We saw in the work of Jones et al that talk such as Dave's could be seen as "cocky" or "overconfident" rather than someone who is actively managing their condition.

### **Minimising Asthma and Symptom Control in a Lifeworld Context**

The idea that, for many participants, a symptom control discourse was more compatible than an asthma prevention discourse, within lifeworld contexts, appeared to have strong links with Cornwell's concept of a "health problem that is not an illness" (Cornwell, 1984, pp. 130-131). In the final extract from the analysis to be presented in this chapter, we can see further evidence for this interpretation but also some of the potential implications of adopting this position within lifeworld settings such as the workplace. Extract Nine presents another type of justification identified in the data. This was a common rhetorical strategy for not taking medications as prescribed, which involved minimising the severity and impact of asthma on everyday life. In the lead up to this extract Martin was asked about the history of his asthma and what doctors and nurses



communicated to him about asthma and medications. Martin's interview was categorised as having accounting style 3 - *Tension between lifeworld and medicine. Adherence potential threat to lifeworld*. The extract is of particular interest because of the strong stylistic assertion in the opening line.

***Extract Nine: 670287 (Martin). Interview 1, page 11, line 35 to page 12, line 7***

1. M: =So I have it has been. But I stress it is not a debili(.)tating (.) problem
2. insofar as my (.) y'know °my work is concerned or my you know my
3. life is concerned. (.) Um (.) I don't play (.) football I do (.)
4. occasionally bouts of strenuous work (1) um but its managed° and I'm
5. very fortunate in that (.) you know I can choose (in the middle?) ((of
6. something?)) what what I do (.) a- at work rather than (.) um (.) you
7. know being in a managerial position I mean I don't wanna (1) y'know
8. er (2) brag but you do have a little bit of flex(h)ib(h)ility um and if
9. there's you know y'know there's somebody else available who will
10. move the grain lorry up and you know I would do his job while he did
11. while he did that (.) and if its unavoidable well I (.) I'll do you know
12. put a mask on and move the lorry myself which is its not an issue as far
13. as I'm concerned (1) you know the guy um (.) you know I can
14. certainly ask somebody else can you just move down (.) while I take
15. over from you= =Everybody knows that the reason I'm doing it I'm
16. not frightened of work but they just (.) I can manage it in that way (.)
17. um (.) so (.) I suppose you could say well actually you are changing
18. your lifestyle but not to that degree.

An analysis of the rhetorical work in the extract demonstrates how Martin deployed several devices to provide evidence to support his claim that his asthma was not debilitating and therefore that he was responsibly managing his condition. He illustrated how he was in control of his asthma by detailing a common scenario at work; a flexible situation that was agreed and understood by his colleagues and that was afforded by his managerial position. Combined with a list of other activities where his asthma was represented as being “managed”, this provided a catalogue of evidence to support the case that “it is not a debilitating problem” (line 1). However, as a consequence of scripting a typical work scenario to demonstrate that his asthma was managed, Martin

can be seen to negotiate a number of positions or “footings”, (Goffman, 1981, pp. 124-159) activated by using this scripting device and which threaten an alternative interpretation of his behaviour. This is evidenced in interactional repair work that Martin displays. First, he can be seen to have orientated to a potential interpretation that the adaptive strategies he used at work show someone struggling to cope with everyday work activities, “its not an issue as far as I’m concerned” (lines 12-13), then, that he is exploiting his employees, “= Everybody knows that the reason I’m doing it” (line 15), and that he is lazy or workshy, “I’m not frightened of work but they just” (lines 15-16). We can see that, in a discussion of asthma management, Martin was simultaneously attempting to construct different versions of his self which included “responsible person with asthma”, “person with health problem that is not an illness”, “conscientious worker”, and “good manager.” Finally, Martin’s assertion that his lifestyle had not changed “to that degree” offered further evidence of a key issue at stake in this discussion of asthma prevention. Whether his lifestyle had changed was not a question put to him. So it seems fair to infer that here he was responding to the framing of this interactional sequence within competing moral discourses of appropriate and responsible illness management, while also responding to different moral discourses from his everyday life, defining what it means to be a good manager and a hard worker.

### ***Blame, accountability and moral discourses in Extract Nine:***

The analysis of Extract Nine demonstrated Martin engaged in justifying his asthma management and also that he had some access to a moral discourse of asthma management which places emphasis on patients to responsibly manage their condition. This was primarily evident in Martin’s account of a typical work scenario, demonstrating a moral agenda to be understood as in control of his condition and to undermine any suggestion he was irresponsibly managing his asthma. This preoccupation dominated key sections of his interview and he could frequently be seen to argue that he monitored and managed his symptoms as necessary, either through a regulation of behaviour, (as seen in Extract Nine), or with the use of prophylactic or relief medication. This strategy therefore has close links with the symptom control discourse identified in Stephen’s account but unlike Stephen, Martin constructed himself as someone proactively managing, or “self-regulating” his condition, rather than reactively responding to symptoms.

This self-regulating repertoire has similarities with the active construction of asthma management that Dave deployed, showing someone engaged and actively managing their condition. Like Dave, Martin could be seen to contextualise his justification of asthma management in a work, and specifically, management setting. Martin's version of his asthma management may therefore be seen as plausible within an institutional discourse of organisational management where he is someone who possesses management skills. However, we can see here that he also has to manage other moralities of his lifeworld. In Extract Nine these different moralities do not appear to fit neatly with a self-regulatory repertoire being deployed where Martin's explanation runs the risk of positioning himself as a manager who exploits members of his workforce for his own ends. This is potentially a rhetorical *cul de sac* for Martin, relying on the listener to provide any discursive space for this tension to pass without confrontation. Martin demonstrated how these competing versions of himself, from medical and lifeworld perspectives, operated simultaneously within the interaction, creating an interactional tension that needed to be managed. There was evidence that Martin orientated to and managed these alternatives thereby validating the importance of these different moral frameworks within the interaction taking place. This insight into the moral dimensions of Martin's talk shows that an approach which would reduce Martin's talk to an attitudinal statement that Martin viewed his asthma as "not debilitating", would miss important insights that have a significant bearing on his use of medications. These are that Martin's decisions about medicine taking may be influenced as much, if not more by a preoccupation in being seen as a good manager; a good worker; and as someone who does not have an illness; rather than just a view of his asthma as not serious enough to warrant regular prophylactic treatment. From a discursive psychological perspective, the "attitude" that Martin's asthma is debilitating is inseparable from these other concerns that he is faced with on a daily basis.

### **Summary of Findings from Face-to-Face Interviews**

The analysis of interview data in this chapter has demonstrated that participants who had a diverse range of explanations for their medicine taking were engaged with a moral agenda when discussing their asthma management. By viewing participants' talk from a discursive psychological perspective, it was possible to readily identify properties in this talk that are not accessible when viewed from an individualistic perspective. Participants could be seen not merely to be describing their asthma management and

medicine taking but also to be engaged in a range of discursive actions, with the objective of presenting themselves, their behaviour and their attitudes in particular ways, whilst undermining competing alternatives. This was evident in the range of rhetorical devices that participants deployed. Key amongst these were the different discursive objects that participants' constructed regarding themselves, their asthma and doctors and nurses. This was achieved by drawing on a range of culturally-available representations of health and illness such as "virtuous ill person", "expert patient", "responsible person with asthma", as well as traditional and well-established conceptualisations of the doctor-patient relationship. In performing these constructions, participants could also be seen to work to undermine potential alternative versions of themselves such as someone having "incorrect beliefs", "disengaged with his/her condition", or "non-compliant." These versions could be seen to interact with other constructions that had origins in lifeworld contexts, such as "someone full up with medications", "hard-working manager", "wealthy benefactor", "rational scientist." These different discursive objects, along with other rhetorical devices, (such as normalising or generalising devices or the identification of external evidence to authenticate an argument), were deployed by participants to construct particular types of explanation, referred to as interpretative repertoires, for their asthma management and medicine taking. This discursive action that participants undertook emphasised the dilemmas that needed to be managed regarding how speakers would potentially be categorised, thereby indicating a moral agenda in their talk about medicine taking.

By highlighting the properties of participants' talk, a more dynamic understanding of talk about medicine taking was possible, moving the analytical focus away from attempts to categorise individuals. In doing so, the problems highlighted in the attempt to identify individual accounting styles could also begin to be addressed. These related to the level of analysis being conducted, being able to identify discursive variation, and how to validate analytical interpretations. The analysis of transcripts reported in this chapter demonstrated how the talk of participants could be seen to be connected despite each account offering very different explanations for their asthma management. This connectivity was seen through the shared moral discourses that were activated within interactions and deployed by participants as interpretative repertoires. These repertoires could also be seen to be multiple and to interact with one another, highlighting both the variation in the sorts of explanations that participants provided and also how different moral discourses were managed simultaneously by participants. Participants' orientation

to competing discourses also provided some validity for analytical interpretations that those discourses were activated within interactions and were pertinent to participants in justifying their asthma management.

A process of analysis which isolates talk into sets of de-contextualised statements, risks categorising that talk in ways which mask the function of that talk within the interaction of its production, and also its function in daily decisions about medicine taking. This type of approach has been seen with individualistic and social cognitive approaches to studying medicine taking, which have been the predominant method to date in explaining non-adherence to prophylactic medications. Viewing talk about medicine taking instead as a form of situated social action, we can see that reported “attitudes” work interdependently in constructing versions of self and behaviour and may reflect attention to multiple concerns about asthma management both from medical perspectives as well as viewpoints circulated within participant’s family, work and other social networks.

### *Moral discourses and the structuring of talk*

The connectivity in participants’ talk emphasised how different moral discourses of illness management and medicine taking circulate over time and in a range of social spaces. The discursive objects participants deployed and the interpretative repertoires they constructed could be seen to have some explicit links with historical and contemporary discourses of asthma management, in particular a discourse of symptom control. A range of participants could be seen to deploy this discourse in explaining non-adherence to prophylactic medications and it could be seen to function alongside other concerns within participant’s lifeworlds. This indicated that a symptom control discourse may be more compatible with other moral discourses of illness management in participants’ lifeworlds whilst a prevention discourse could pose a threat to participant’s roles and activities in everyday life.

Deploying a symptom control discourse could be seen in conjunction with speakers constructing the authoritative version of their asthma, functioning as a key rhetorical device, for several participants, in managing blame and accountability regarding their medicine taking. Constructing the authoritative version of asthma to indicate speakers responsibly managing their condition, provided evidence of a moral discourse of asthma

management, reflecting tensions identified in asthma guidelines which positions clinicians and patients as simultaneously empowered and responsible. There was also some evidence that participants reproduced notions of the educated patient evident within asthma guidelines whilst notions of shared decision-making, or concordance between doctor and patient were less evident. As was discussed in Chapter Two, the language used in asthma guidelines represents a bureaucratic manifestation of institutional tensions between evidence-based and patient-centred medicine. However, whilst these twin concerns may be particularly acute for clinicians in making decisions, the evidence in the interview data suggested that participants' talk had more coherent links with other recognisable, culturally-available, moral discursive frameworks of patient and doctor roles, rules and rights as well as other discourses of illness management that circulate lifeworld contexts. In the data analysed in this chapter these discourses included: versions of a Parsonian sick-role; the expert patient; consumerist and management discourse; a cultural discourse on what it means to be sick; a work-ethic discourse; and a rehabilitation discourse. The purpose of the analysis was not, in a Foucauldian sense, to detail the range of discursive objects, concepts and statements, which are associated with these different discourses. Rather the aim was to indicate different moral discourses which appeared to be activated within interactions, could be seen to be managed by participants, who attempted to position themselves and their behaviour within those discourses.

Being accountable for one's health, whilst a notion clearly evident in asthma guidelines, is a moral concern reflected within a variety of discourses of health and illness and it is these different moral discourses towards which participants appeared to orientate their talk. However, the analysis also showed that the discourses which participants drew on were not exact replicas of these discourses but were constructed to meet particular interactional demands on them to justify their medicine taking. The identification of interpretative repertoires was used in the analysis to emphasise this "loose coupling" (Goffman, 1983, p.11) between systemic structure and individual utterance. Doing this indicated how notions of morality, illness management and medicine taking may circulate a wide range of social spaces which structure talk in interactions about medicine taking but which may be creatively used to meet a range of interactional concerns. In addition the different repertoires that participants constructed appeared to have multiple origins and functioned interdependently in talk about illness management. This manifestation of the different moral dimensions in such talk may indicate that the

issues that influence medicine taking decisions may be as likely to originate in everyday life as in individuals' understandings of asthma and associated medications.

***Limitations of interpreting the interactional issues and role of morality in participant's discourse from interview data***

The extracts from the face-to-face interviews provided examples of how participants in the study could be seen to deploy rhetorical devices to position themselves within culturally-available discourses of appropriate health-related behaviour. However while the extracts reported so far clearly provided evidence that these participants were preoccupied with justifying their behaviour, not all participants simply reproduced the type of rhetorical defence of their medicine taking being sought in this study. The analysis also yielded three interviews where there were few rhetorical devices being deployed by participants and which did not follow the pattern identified in the body of the data. We also need to know what can be learnt from interviews where participants do not appear to be justifying their medicine taking and whether this can inform the patterns so far reported which highlight a moral agenda in participants' talk.

In Chapter Five, sequences of interaction are discussed which show examples of participants deploying few rhetorical devices to account for their asthma management. These extracts will be seen as difficult to analyse using the discursive psychological framework set out thus far in this thesis. The reasons for this difficulty will be explored enabling the role of moral discourses in the talk of participants to be contextualised. Developing a richer understanding of the circumstances under which participants' justified their asthma management suggested that, in order to generalise about the interactional issues faced by people when talking and making decisions about medicine taking, we might need to obtain data based on a different set of interactional conditions to the interview data. This will be the topic of Chapter Six which will analyse data collected from a focus group in which data was shared with participants. These additional data will then enable a discussion in Chapter Seven of the importance of considering interactional issues and morality to better understand talk and decisions about medicine taking.

## Chapter Five

### Contextualising the Role of Moral Discourses in Talk about Prophylactic Medicine taking

*D: SORRY I'M NOT VERY HE(h)LPFUL*

*JM: NO YOU ARE NO NO WHAT I WANT TO DO is understand your point of view.*

(670289, Interview 1, page 23, lines 38 to 40)

In the previous chapter, data were presented which demonstrated evidence of the interactional issues and role of morality in talk about medicine taking. Participants' talk could be seen to be structured by a moral discourse of illness management as well as other lifeworld discourses. However, Chapter Four concluded by introducing some of the limitations in interpreting the role of morality to how people with asthma and other chronic illnesses talk about prophylactic medicine taking in interactions outside of the interview setting reported in this study. These concerns were related to how the face-to-face interviews came about and were set up. This chapter will attempt to address some of these concerns, beginning by analysing extracts from interviews where participants did not appear to be justifying their medicine taking behaviour. Key features of these interviews, which led to this interpretation, were that they lacked a "qualitative" narrative; involved a lot more turn-taking and input from the researcher; and were shorter interviews than those interviews where participants provided long narratives and extensive explanations for their medicine taking.

This analysis of "deviant cases" led to the interpretation that one reason that participants, within interviews, might justify their medicine taking would be if they had access to the particular framing of the interview that the interviewer was attempting to activate. The following section describes how this interpretation was investigated by examining evidence of interactional misunderstandings in the deviant cases. It will then demonstrate how an analysis of the conditions of the interviews may enable insight into potential misunderstandings and the circumstances under which participants were likely to justify themselves. This discussion will then be used to provide the rationale for the



additional data that was collected in this study in which interview data was shared with participants in a focus group. This will be the topic for Chapter Six.

*Talk about medicine taking deploying few rhetorical devices*

In this section two extracts are analysed to provide insight into why some participants did not appear to justify their medicine taking as expected. These extracts were chosen because they provided two very different types of interaction which appeared to result from a mismatch in resources between researcher and participant. Each extract can be found as part of a longer excerpt in Appendix B and the full transcript for the interviews included in this chapter are available on a CD as an appendix. As with the earlier extracts discussed in Chapter Four, the excerpts enable the choice of interactional sequences to be examined and facilitate further insight of how participant's versions were sequentially constructed within the interactions taking place.

In Extract 10, Dawn was responding to a request from the interviewer to clarify her views and that of her doctor regarding the use of the brown prophylactic inhaler. In contrast to the extracts presented in Chapter Four, there was much less evidence of the use of rhetorical devices that might suggest a moral discourse of asthma management was dominating Dawn's account. Throughout the interview, Dawn seemed to minimise the importance of asthma for her. However, whereas Martin (for example, in Extract 9 of Chapter Four), constructed a typical work scenario to manage potential accusations of irresponsibility in not taking his prophylactic medication, Dawn can be seen to offer a much more straightforward explanation. As with other interviews, the researcher sought to uncover any tensions between the participant's presentation of how they managed their asthma and any clinical guidance they had received regarding their asthma management. Extract 10 presents an attempt by JM to go over earlier comments to pursue these points further because little such material had been previously obtained, despite there being a strong indication and assumption by JM that a tension existed between Dawn's perspective and the medical perspective and that Dawn would orientate to this.

*Extract 10: 670289 (Dawn). Interview 1, page 18, line 51 to page 19, line 36*

1. JM: And and (.) the (.) um do you talk to him about how you use (.) the

- 2 . brown inhaler we talked about that briefly before um (.) and he said  
3 . that you should take that (.) to did he say that you should take that  
4 . every day or (.) a long period or did he how did he say you should use  
5 . it over a long period of time (.) cos you sort of mentioned did you  
6 . mention to him that you stopped using it
- 7 . D: Yes yeah (1) ahhh well he sort of (.) hhh ((sounding slightly  
8 . exasperated)) I mean his advice is really that I should use it (.) all the  
9 . while and its totally down to me that I don't because his advice to me  
10 . is (.) to use it (.) y'know most of the time but I mean I feel fine without  
11 . it I don't really know why I need to use it because without using it (.)  
12 . I'm alright I don't get breathless or get any asthma symptoms
- 13 . JM: And do do you actually share that view with him or
- 14 . D: Yes he know I stopped using it yes yeah (.) spose he just you know he  
15 . just (.) said you know if I you know its up to you really (??) SO I I  
16 . MEAN IF I'M IF I'M do have a bad attack alright I will start using it  
17 . (1) for any reason um (.) have a bad attack but (.) normal run of the day  
18 . things I don't (.) I don't want to use it (.) hh every day
- 19 . JM: I'm just trying to understand why exactly heh heh ((slightly nervous  
20 . laughter))
- 21 . D: WELL I I DON'T KNOW I THINK ITS JUST AS I SAY ITS JUST  
22 . THE THOUGHT OF TAKING IT EVERYDAY WHEN I DON'T  
23 . REALLY FEEL I NEED IT
- 24 . JM: °Okay that's fine°...

If we analyse this extract using the analytical tools developed and used in Chapters Three and Four to look for evidence of Dawn justifying her medicine taking, limited evidence emerges that Dawn was deploying a range of rhetorical devices and interpretative repertoires to account for her medicine taking. We can see that Dawn does display an awareness of a potential tension between her view and medicine with use of the modal “should,” perhaps triggered by JM’s own use of should. However, in contrast to extracts in Chapter Four, Dawn didn’t seem to manage these potential tensions any further other than to say that her doctor said she could do what she liked. Dawn seemed to avoid being too confrontational with phrases which hedged her position - “sort of”, “yes he know...” and switched from a position that perhaps blamed herself for not

following her doctor's instruction "down to me" to one which was more empowering "up to me". There was little evidence that Dawn was preoccupied with managing different moral positions in her talk about her asthma management, despite being aware of potential tensions between her view and medicine's, instead simply asserting her view in a very clear voice, (lines 21-23).

This extract can exemplify two interpretations of Dawn's account of her asthma management. The first of these was that Dawn's ability to justify her medicine taking was constrained when she had to reproduce the voice of medicine, spoken through the voice of her doctor. This resonates with the extracts within Stephen's interview, where he could also be seen to orientate to the perspectives of doctors and nurses. Stephen explained his non-adherence to prophylactic medications by blaming himself for his decisions and positioned clinicians as "banging their head against a brick wall", (Extract Four). This explanation was set within a lengthy discussion of his problems in managing his asthma and complying with prophylactic medication. In the case of Dawn however, the voice of medicine was possibly constraining her ability to provide an intelligible narrative. In both Stephen's and Dawn's accounts there was a lack of rhetorical work evident in explaining how they managed their condition. In contrast to Stephen, where his self-criticism appeared to require little defence within a moral discourse of remorse and rehabilitation, Dawn's lack of rhetoric was perhaps more to do with alternative lifeworld discourses being restricted by the voice of medicine that acted out the clinical discourse of asthma management. These types of distinctions were identified in a number of extracts within and between interviews and formed part of a separate analysis on the concept of "discursive space" between structure and agency. This work has not been reported in depth in this thesis but some analytical notes have been included in Appendix D.

The second interpretation of Dawn's account, which can perhaps be seen in conjunction with the first, is that Dawn did not frame the discussion as a "qualitative interview" where participants are often expected to talk at length about their experiences and viewpoints. To obtain evidence to support this interpretation required an alternative analytical technique to the discursive psychological tools available up to that point. This was because the analytical focus was to seek mismatches between the interviewer's and Dawn's understanding of the encounter rather than to identify rhetoric. Such an alternative interpretation was enabled by drawing on the concept of contextualisation

cues from interactional sociolinguistics (Gumperz, 1999). Contextualisation cues are signals (verbal and otherwise) to indicate what context is being referred to within an interaction and which are relied upon in everyday interactions to interpret the intention of the speaker. In Extract 10, JM asked Dawn to resolve the apparent tension between her own decision to stop taking the brown inhaler and the doctor's advice that she "should" be taking it. The presentation of this potentially difficult issue for Dawn, the specific context being referred to, was set within a long wordy opening question, which suggested a problem, rather than directly point out the issue that needed addressing. Phrases were deployed by JM to highlight the specific context, using the modal verb "should" to activate the medical voice and "did you mention" to position Dawn's own previously iterated position. However, Dawn seemed exasperated by JM's continued questioning on this point, perhaps either because she felt she had already provided an answer and had nothing to add, or did not appreciate the point that JM was trying to get at. This appeared to be an insufficient response for JM who then made another attempt to get the response required with a further contextualisation cue – "do you actually share that view with him" (line 13). However, Dawn still didn't address the issue, of her and the doctor having different views, in a way that appeared satisfactory for JM. As a result, another bid for the information was made in line 19, with the nervous laughter suggesting the interactional tension was increasing. Dawn then stated very loudly her position but only after saying 'I DON'T KNOW' (line 21), which again suggested she didn't see the point being sought. This appeared to demonstrate increasing pressure for Dawn to say something assertive about her view, which then led to a rapid retreat by JM, "Okay that's fine" (line 24). This signalled a different contextualisation cue, that JM would stop asking this question and that they were now moving to another topic. Although Dawn provided a clear reason for not wanting to take the brown inhaler, spoken in a louder tone, her lack of elaboration on this point was not what JM as the interviewer was expecting or hoping for. Her inability to meet this framing suggested that she was not able to access or utilise the particular discursive framework of asthma management that JM was constructing within the interaction, summed up towards the end of the interview in Extract 11:

***Extract 11: 670289 (Dawn). Interview 1, page 23, line 38 to 41***

1. D: SORRY I'M NOT VERY HE(h)LPFUL
2. JM: NO YOU ARE NO NO WHAT I WANT TO DO is understand your

3. point of view.

The next extract demonstrates another example of an interview where the talk of the participant suggested that the interviewer's (JM) understanding of the interview, (how it should have proceeded and what it was about), was not shared by the participant. As a consequence, the interview appeared to lack the sort of narrative and rhetorical devices identified in other face-to-face interviews, perhaps indicating that there was little justification of asthma management. In contrast to most of the face-to-face interviews the interview with Janet (J) took place at her local surgery. In Extract 12 we can see evidence that this different location appeared to set up a particular expectation of how the interaction would proceed.

***Extract 12: 650405 (Janet). Interview 1, page 8, line 14 to page 10, line 51, local surgery***

1. JM: Your inhaler um again I'm not here to sort of say
2. J: No
3. JM: why aren't you using it but why did you decide not to or why did you
4. decide
5. J: Well I think I probably I did forget to take it first thing in the morning
6. sort of thing I think that was half of it and you know if you felt alright
7. you sort of didn't think to take it it weren't not very often
8. (3)
9. JM: Ok. Um and have you been did you go back to the doctors after?
10. J: I think I probably had to go back to check that everything you know
11. was alright I'm sure I did. He wanted to check you know to make sure
12. it was alright (1) yeah
13. JM: And what did he say do you remember
14. J: He said that was y'know sort of carry on with your inhalers and
15. y'know take them how you should sort of thing
16. JM: You say you've been doing that for about 30 years?=  
17. J: =°Yeah°
18. JM: (??) um okay and the first time you changed was when you entered this
19. study
20. J: Yeah

21 . JM: What made you um decide to take part in the study was there  
22 . J: Well I I think I don't know if I had a letter or they rung me up  
23 . JM: Yeah  
24 . J: And I said providing that worked round me sort of thing I could do it  
25 . JM: And you were happy to try something different  
26 . J: Yeah  
27 . JM: And um so you've been taking the tablet for  
28 . J: A couple of weeks I think (1) I think I'm on the (1) cos there's four  
29 . strips I think in the packets I think I must be now on the third strip  
30 . JM: Right  
31 . J: something like that  
32 . JM: And how's that going  
33 . J: Alri↑ght yeah  
34 . JM: You're sort of  
35 . J: I think I've got to go and see her again oh I forget I've got it in my  
36 . diary  
37 . JM: It's a few weeks wasn't it  
38 . J: Yeah.  
39 . ((searches in bag for diary))  
40 . JM: That's alright don't worry it's a few weeks isn't it  
41 . J: Yeah that is the 20<sup>th</sup> it's when I'm starting a new job I think  
42 . JM: Yeah  
43 . J: I'd better tell them I might be a bit late well I aint gonna be long here  
44 . about half an hour  
45 . JM: Yeah  
46 . J: I've only got to go a little way up there so it aint far away  
47 . JM: That's handy  
48 . J: Yeah  
49 . JM: Um but you manage to remember to take it every [day or]  
50 . J: [Yeah] (1) well I try to heh heh heh  
51 . JM: Yeah. How would you compare the tablets with the inhalers  
52 . (3)  
53 . J: Al. Alri↑ght  
54 . JM: Do you think there's any differences?  
55 . J: Er (2) they don't seem to have no side effects or something (2) so long

- 56 . as I remember you know try to keep remembering to take one you have  
57 . to to take one at night don't you  
58 . JM: Yeah  
59 . J: Yeah  
60 . JM: And how do you think they work do you feel that they work  
61 . J: Ye↑ah. (2) Yeah  
62 . JM: How have you noticed just how long it takes sort of thing  
63 . J: Um. .hhhh hhhhhhh um no I took them I take them alright and they I  
64 . seemed alright y'know after I took them and that so  
65 . JM: But, you said you mentioned the brown inhaler took about a week two  
66 . weeks  
67 . J: Yeah I think that was when I first had it I suppose to get use you know  
68 . JM: Get used to it  
69 . J: Yeah get used to them

Extract 12 is typical of how quickly turns were taken in this interview, with Janet's responses amounting to a few sentences at most and leading to a higher number of turns and the talk being approximately evenly shared between interviewer and participant. This is a notable contrast to other interviews where participants did most of the talking in long responses to questions. In the lead up to this extract, Janet verbally completed the Medication Adherence Report Scale (MARS), was asked about the circumstances surrounding her diagnosis of asthma and was then asked to explain when she was first prescribed the brown inhaler and her experiences of using it. As with the extract presented here, Janet provided short explanations and descriptions of the events. This extract was interesting for the analysis as JM attempted to directly address the issue of non-adherence in line 1. However, the context for this question was specified "again I'm not here to sort of say why aren't you using it". This contextualisation cue provided a reframing of JM's role "I'm not here to" and the normative expectations of what Janet could and could not say about her medications within this interaction. Providing a reframing suggested that Janet had not done what was expected up to this point in her talk about asthma. In other words, she hadn't provided a long account of her asthma and decisions about medications and didn't seem to be justifying any of her behaviour. Despite this reframing by JM, Janet provided a straightforward response with few rhetorical devices being deployed. Her forgetting is set within an historical context of having had asthma for 30 years, potentially distancing her current asthma management

from any decision that she made. However, Janet also offered little explanation of her motivations for taking part in the current asthma study (line 22), or of how she had experienced the new tablet treatment (lines 51-69). In each of these three responses Janet presented a simple description of events. What is notable in these simple descriptions as with her talk elsewhere in the interview is that her responses stuck closely to the question and once that had been addressed she ceased her response. This was in contrast to other interviews where a question was often followed by an elaborate response, often bringing in different aspects of the person's lifeworld and views of issues outside of asthma. Here, Janet consistently stuck to the specific question with virtually no elaboration.

If we view Janet's talk as accurately reflecting how she engaged with her asthma, then one interpretation of this interaction could be that asthma does not play a big part in Janet's life. From a medical perspective with an objective to get patients to adhere to her medications, she appeared to be happy to follow whatever instructions she was given and perhaps just needed a little reminder of the need to adhere to her prophylactic medication more regularly. However if we view this interaction as a product of the social, historical and interactional context then we can see evidence that Janet was responding to the dialogical expectations of a particular type of interaction. The short responses and frequent turn-taking appeared much more like an asthma review consultation than a qualitative research interaction. Asthma review consultations typically check patient's symptoms and how they are using their medications. Janet checked how often she needed to be taking the tablet (line 56-57), started to check her diary for study visit dates (which function as asthma reviews) for the main asthma study (line 39), detailed how many "strips" there were on her prescription (lines 28-29) and provided responses that did enough to affirm that the medications were ok and working (lines 33, 53, 61). We can see how this framing of the interaction was jointly constructed by JM and Janet, as JM filled the spaces between Janet's talk with further questions or clarification, functioning to reinforce that this was a "checking" type of interaction. There was also evidence of a moment of tension as JM attempted to move on from this "checking talk" by providing answers for Janet (line 40). Unfortunately, this only served to reinforce the dialogical expectation being mutually constructed (lines 35-48).



However, when viewing this extract from within the social space in which it took place, a new and very different interpretation of this interaction is possible. The interview not only took place within Janet's local surgery but was conducted in a doctor's consulting room which Janet had previously attended for an asthma consultation with a nurse. The interviewer, sat in the clinician's chair next to a computer, asked direct questions about Janet's asthma as she sat in the "patient's chair". This ethnographic context appeared to set up a communicative expectation within the interview which was closer to that found within an asthma review than a qualitative interview. When viewing Janet's talk as a qualitative interview, her lack of narrative appeared to indicate a lack of justification for her asthma management. However, if we now view the interaction as an asthma review then we can see that Janet was indeed engaged in demonstrating that she was appropriately managing her asthma. This was evidenced by the checking talk that took place, including Janet counting medication strips, repeating the prescription's instructions and indicating she had recorded appointments by searching for her diary.

One interpretation of the uncomfortable moments in the two extracts presented here is that there were mismatches in expectations between the interviewer and interviewee about the meaning of the interaction. One purpose of the face-to-face interviews was to elicit a narrative from participants to enable understanding of how and whether "lifeworld" discourses might conflict with medical discourses of asthma management and adherence. The moments of tension in the two extracts suggested that neither participant was engaged with this presupposition and was therefore not doing what was expected within their respective research interviews. This was evident in Dawn's and Janet's responses to contextualisation cues provided by JM, suggesting that one way to gain insight into when participants do or do not justify their medicine taking would be to examine how both researcher and participants perhaps understood what the interviews were about and how the research interview as a method regulated what participants were able to say.

## **Analysing Interactional Conditions in which Participants Justified Medicine taking within Face-to-Face Interviews**

A technique which was used to gain insight into mismatches in how researchers and participants “framed” interview interactions was to analyse some of the interactional conditions of the face-to-face interviews. Ideas from linguistic ethnography (Rampton et al., 2004) were drawn on in conducting this part of the analysis. This is because approaches that have been associated with linguistic ethnography (LE) have shown a way to unite a range of linguistic and ethnographic disciplines when studying communication. A scholar, whose ideas have been used to critique research interviews from an LE perspective, has been Charles Briggs. Briggs, who has worked to combine linguistic and medical anthropology with social anthropology in a range of fields, provided a sociolinguistic appraisal of research interviews in “Learning how to ask” (1986). Here Briggs highlighted a number of areas that can be investigated to understand these conditions in research interviews. Using data from his own interviews Briggs demonstrated how “communicative blunders” (pp. 39-60) over contextual or indexical meanings are a frequent occurrence in interviews, revealing a divergence in and lack of access to each member’s presuppositions, goals and framings of the purpose and meaning of the research interview and its communicative procedures. This is set alongside a transformative process whereby participants are asked questions which force them to artificially summarise and provide abstract meaning from everyday experiences, a process which bears little relation to the experience itself. Briggs argued that researchers frequently fail to recognise these processes and as a consequence interpret participant’s talk in ways which typically fit their own conceptualisation of the interview and which mask indexical meaning by asserting its content as “real.”

To analyse some of the conditions of research interviews that Briggs sets out required a different analytical approach to the one set up so far. The reason for this is that the discursive psychological methodology taken to analyse rhetoric in talk has a particular conceptualisation of context which was limited for the purposes of analysing the interactional conditions of interviews. The discursive psychological view is that while wider discourses may shape interactions, context is produced by participants through the interaction and is made pertinent to the analysis by participant’s own orientation to particular discursive issues. We saw this in the analytical path that was traced between

the identification of moral discourses in asthma management in Chapter Two and the rhetorical talk about medicine taking of the participants in this study. This analysis of moral discourses was based on a theoretical link between discourses that circulate cultural and institutional spaces to the activation and regulation of interactional talk. This was therefore a view of context that limited its analytical lens to a linguistic analysis, which although providing much that is rich about what happens when people talk about potentially contentious issues, was limited in its ability to specify the roles, presuppositions and communicative expectations that had preceded and been set up within the interview. Instead, a view of context was needed that allowed an examination of features that were not apparent in a purely textual analysis of interview data, but required going beyond the transcript itself. This meant attending to more ethnographic features of the research interview that may have played a key part in what was said within face-to-face interviews.

One useful way to conceptualise these features of context can be found in the work of Jan Blommaert. He argued that a purely textual analysis fails to account for “forgotten contexts” (2005, pp. 56-57). These contexts are not features of single texts but are of “larger economies of communication and textualisation” and offer additional evidence that bridges the gap between social structure and its manifestation in talk and text. It is the analysis of these forgotten contexts that are now discussed to enable an understanding of how researcher and participant’s presuppositions, goals and framings of the research interviews may have been divergent. This analysis of what participants brought to these interactions enabled the interactional conditions in which participants were likely to justify their asthma management and medicine taking to be specified.

### **Interactional Conditions of the Face-to-Face Interviews**

Attending to several interactional conditions here helped suggest that misunderstandings were likely to occur between researcher and participant. Revealing these misunderstandings indicated that justifying medicine taking was dependent on participants having access to and utilising linguistic resources regarding their involvement in the study that were not directly referred to within the interaction but which were implicit within the larger economies of communication and textualisation to which Blommaert refers.

### *Pre-textual identities*

The first interactional condition to attend to relates to the process of recruitment for the interviews described in Chapter Three as set within the context of a large, randomised controlled trial (the ELEVATE study). To be interviewed, participants needed to be categorised in all of the following ways, determined by a mixture of objective breathing tests and questionnaires:

- A person with asthma
- A person with inadequate quality of life
- A person with inadequate asthma control
- A person who is non-adherent to medications

These “pre-textual” identities were not explicitly made reference to within interviews, or at any point in the participant’s involvement with the ELEVATE study, but were implicit in the process of recruitment and eligibility described in Chapter Three.

The talk within Dawn’s extract suggested that JM attempted to activate the pre-textual identities that had been constructed through Dawn’s participation in the main asthma trial. These were indicated by JM’s asking Dawn about her reluctance to take the brown inhaler and how this fitted with her doctor’s viewpoint. However Dawn was not able to respond to JM’s contextualisation cues and her lack of access to or use of these contextual resources resulted in a very different type of interaction. If we contrast this with the extracts in Chapter Four, we find much stronger evidence that these pre-textual identities were activated in the interviews with Martin, Irene, Stephen and Dave, and that they responded accordingly. In contrast to Dawn’s talk, Janet demonstrated clearer evidence of a moral agenda in her talk. However, unlike the interviewees discussed in Chapter Four, Janet’s talk was not orientated to justifying previous actions but instead involved her presenting herself as compliant with her current asthma therapy. The pre-textual identities that JM attempted to activate were therefore re-framed within a context of an asthma review consultation leading to another type of interaction taking place. This indicated that pre-textual identities were activated within interactions and engaged with by participants in a number of ways, appearing to play a key role in influencing whether participants justified their medicine taking.

### *Researcher and participant presuppositions*

The second interactional condition of the interviews, which may have influenced how participants talked, was related to the different presuppositions held by the researcher and participant about the resources and goals that each member brought to the interview setting as well as their understanding about what happens within research interviews. The goal of the interviewer was to elicit data on the discursive construction of medications and views of health and illness. The goal of the interviewee, by contrast, might have been to have a chat, help out, get something off their chest, to finish the interview as quickly as possible, or to get some evaluation of their own opinions or position. The interview questions set out in the interview schedule (Appendix A) constructed normative expectations about how participants engaged with their asthma, their goal for participation in the interview and what they were able to say about their asthma. Even the loosest questions aimed at eliciting narratives “tell me about your views on illness” suggested that the participant should be able and willing to discuss a view on illness. This potentially constrained participants’ narratives to a format that they may or may not have been able or happy to participate in. This could be seen in how the interview schedule focused on asking questions about what was told to participants by doctors and nurses, how well it was done and how they felt about having an asthma diagnosis and prescription of medication. There was a presupposition that because they did not take their medication as prescribed, participants should have had a grievance about their health treatment and that the interview offered an opportunity for participants to express those grievances.

Both researcher and participant had potentially very different understandings about what a “research interview” was about, which were therefore likely to lead to misunderstandings. Using the term “interview” with participants to describe the conversations taking place, imposed a set of conventions on that situation, not only about who should ask the questions but what sort of questions were to be asked, i.e. open-ended questions aimed at eliciting narratives. Participants may have or may not have been familiar with this particular genre (Duranti, 2001) and whether they had such familiarity may have influenced how they participated within it. In addition, there were different activities within the interviews which set up different interactional expectations. Generically, this was a research interview and specifically a qualitative interview. However, participants were also asked to complete the Medication

Adherence Report Scale – MARS (Horne & Weinman, 2002). This was sent by post but was reviewed at the beginning of the interview. In contrast to the qualitative interview it required short responses. There was therefore a mix of activity types that required different types of responses, or “production formats” (Goffman, 1981) potentially leading to misunderstandings about which production format was appropriate and when. Janet’s interview began with her verbally completing the MARS questionnaire, as she had not already completed it by hand. This may have set up a particular expectation about the type of response required which, along with a possible lack of familiarity of qualitative research interviews, may have contributed to her framing that interaction as something akin to a clinical consultation.

In addition to problems being raised in switching production formats across activities, participants’ talk could also be seen to be controlled within activities, regulating the type of talk that was produced. The standard interview format of question and answer sets up a particular interactional sequence which regulates what interviewees are able to talk about and how they deliver it. Qualitative interviews typically involve a series of sub-sequences which follow a particular pattern. Frequently the interviewer begins with an opening question from the interview schedule, provided with a contextualising preface. This is often followed by a narrative from the participant with the interviewer providing listening confirmation cues. Possible clarification questions interrupting the narrative sometimes occur and then the interviewer may use follow-up questions to pick up again on something said earlier in the narrative.

We can see this type of pattern in the transcripts of the face-to-face interviews (Appendix B and CD). The interviewer was seen to control the rhythm of the interview and also to select what the issues “are” in participant’s talk which, although open to cues from the interviewee, decided what needed to be followed up and focused on. This was evident in the researcher’s preoccupation with participant’s reasons for not taking their medication. The choice of questions in the interview schedule that met this purpose therefore controlled the boundaries of relevance in what and how topics, set out on topic cards, were discussed and later, what was analysed and “seen” in the data. This structuring of talk therefore regulated the production and interpretation of the role of moral discourses in talk, further influenced by how talk was captured within the interview, documented as “data”, subsequently analysed and produced for a particular audience. Face-to-face interviews were recorded on tape, taken away to be transcribed

with a limited set of transcription conventions and analysed at a later date for the purposes of a PhD thesis. Much of the richness and nuances within the original verbal interaction were lost as a result of this process. Data were therefore “made” rather than provided and ran the risk of decontextualising how moral discourses were produced within interactions, minimising the possibility of alternative interpretations of that data.

As a researcher on the ELEVATE study, participants potentially viewed the author’s (JM) role as an expert on asthma. This framing of the researcher’s role combined with an interview format of direct questions potentially reproduced the individualising discourse being critiqued in this study, demanding that participants justified their medicine taking behaviour. The use of the MARS questionnaire may have reinforced this by activating an “adherence discourse”. Similarly the act of setting up a one-to-one interaction which was about “your asthma”, may also have called for participants to provide morally acceptable explanations for the decisions that they had made. As Radley and Billig (1996) point out, being interviewed by a presumably healthy and employed “health researcher” about one’s health-related behaviour will create a particular type of interactional dynamic whereby interviewees are faced with a dilemma of presenting themselves as fit for work yet presenting with authentic symptoms and not a “malingerer.” Consider the following extract taken from the interview with Martin discussed in Chapter Four. The sequence shown in Extract 13 followed shortly after Extract 9 in Chapter Four which demonstrated Martin orientating to a variety of concerns with his health and his work.

***Extract 13: Participant 670287, (Martin). Interview 1, page 12, line 11 to line 47***

1. JM: Um (.) Um when you entered the study (.) and you were randomised to
2. the (.) brown inhaler=
3. M: =↑Mmhm
4. (1)
5. JM: did the nurse talk about how she would like use it=
6. M: =Yes
7. JM: °What did she say°
8. M: She said morning and night
9. (.)
10. JM: °What did you say°

- 11 . M: I said fine. if its part of the study, of course I'll do it
- 12 . JM: And and [have]
- 13 . M: [And ] I have been doing it
- 14 . JM: °And how long's that been, how long have you been on it°
- 15 . (1)
- 16 . M: With the study you should have the de↑tails of that=
- 17 . JM: =I have but its in my car=
- 18 . M: =Right [okay]

The latched responses and softly spoken, yet direct questioning, resemble what might be found with a witness taking a stand in a courtroom. What is important here is that the participant, Martin, didn't seem to pick up the framing of this questioning as asking about the nurse's behaviour and not his. Rather, the defensive work suggested that he considered it an interrogation of his behaviour, potentially seen as continued from the earlier discussion. This was indicated at lines 16-17, where Martin appears to regain some authority within the interaction by initiating a reverse in the turn-taking sequence followed by JM's own rather weak latched response.

The author's role as both researcher on the main asthma trial and qualitative research student had the potential to seed a mixture of cues within interactions. Participants may have seen the interview as either an interrogation of their asthma management, an opportunity to air grievances or as something else entirely. The direct questioning about a failure to take prophylactic medications had the potential to exacerbate any tensions whilst providing a barrier to different contrasting framings of the influences on participants' asthma management that the interviewer attempted to construct. Participants were therefore likely to differ in how they understood the dialogical expectation set up within the interview and would differ in how the linguistic resources available to them were utilised in a discussion of their asthma management. This would make for lack of clarity in what was required from interviewees and there was a range of evidence that there was gap between the researcher's expectations and how the participants framed the interactions, evidenced with statements such as "that's why I felt that perhaps I was wasting everyone's time, you know, by doing this survey" (530181, page 1, line 50 to page 2, line 2), "SORRY I'M NOT VERY HE(h)LPFUL" (670289, page 23, line 38). It is therefore possible that lack of access to the interviewer's agenda



(and *vice versa*) and to the linguistic tools of adherence may have created some of the interactional tensions and misunderstandings apparent within the data.

## **Summary**

Being asked to provide a long narrative about one's asthma was likely to be an unusual occurrence for many participants in this study. The research interviews, while well-defined from an academic perspective, may well have had vague boundaries and definitions for participants. Whilst participants may have had some similar discussions with relatives and friends about their asthma they would have been unlikely to have participated in a discussion where their asthma management was the sole focus of attention. Although individuals' asthma management is the focus of discussion in asthma consultations, this research encounter with a relative stranger was, unlike clinical consultations, one which they had not initiated. The topics of discussion, agendas of the researcher and participant, backgrounds, experience and roles were potentially unclear and the style of questioning could be seen to be interpreted in a number of ways including as an interrogation of the participant's asthma management.

Without the presence of well-defined parameters and criteria for discussion that were easily accessible to participants, it is conceivable that those who justified their medicine taking may have been responding to a particular set of interactional conditions that were activated within those interviews. These conditions were an individualising discourse within a research context which had recruited participants based on their asthma being categorised as inadequately controlled and one which could have positioned participants as blameworthy for that inadequate control. For many participants, being interviewed by someone, working on that study, about their medicine taking decisions was therefore likely to activate issues of blame and accountability about those decisions. In contrast, participants who did not appear to deploy many rhetorical devices, either blamed themselves (in the case of Stephen); framed the interaction as a clinical review (and therefore adopted a different style of rhetoric); or appeared uncertain as to the purpose of the discussion and unable to utilise the necessary resources to justify their medicine taking.

The "researcher" and "participant" in this study were institutionalised roles formed through medicine and scientific research that were implemented through research

interviews. The purpose of the interview, the roles, rules, rights, communicative expectations and responsibilities of the participants were therefore external constructions that were partially and unevenly activated within the interview interactions. In addition, both researcher and interviewee brought their own differing theories, presuppositions and expectations about what the interactions were about. These constructs therefore moved across time and space and had an influence across contexts. The resources available to interviewer and participant were likely to differ and yet it is the interviewer who set the normative expectations of what was expected from “a person with asthma who is discussing health, illness and medications.” The justification of medicine taking within interviews was therefore intimately connected to participants’ ability and willingness to access the resources that the interviewer possessed and attempted to activate within the interaction. These attempts were not explicit statements but could be seen through the interviewer’s use of “contextualisation cues.” Similarly, participant’s framings were constructed in the dialogue. These framings were also not made obvious because of their lack of explicit discussion within the interaction taking place. These insights therefore raised uncertainties for the author in the ability to extend claims about the role of morality in participant’s talk beyond the face-to-face interviews to other types of interaction about prophylactic medicine taking. Such uncertainties posed an analytic requirement to identify data that could be considered “new” which could be used as further evidence that participants and people with asthma engage with notions of morality when discussing prophylactic medicine taking. Chapter Six reports findings from a focus group where data from the face-to-face interviews was shared with participants. The focus group could be considered as providing new data because a different interactional dynamic was constructed from the interviews, building on the lessons learnt from the analysis reported in this chapter. These new data were then analysed to identify evidence of whether moral discourses of medicine taking might also be activated and which would therefore enhance the plausibility of interpretations generated from the face-to-face interviews.

## Chapter Six

### **Analysing Interactional Contexts in a Data-Sharing Focus Group**

Viewing talk as a product of interactions between people raised challenges for indicating how the participants in this study might have talked in a different type of interaction than interviews. Taking into account the conditions under which the research interviews took place entailed interpreting the role of morality in that talk as unique to that particular form of interaction. Deriving more general statements about the role of moral discourses in a range of everyday interactions about illness management was not possible without some comparison of talk in another kind of interactional space offering a different type of data that could also be seen to find moral discourses in talk. This is a distinct departure from positivist notions that a specific sample size is needed to generalize to a wider population. Here, talk was viewed as implicitly linked to systemic discourses that circulate through society within different interactions, social networks, and institutional and cultural settings, and which structure that talk. Talk about health and illness can be seen to be a product of discourses which are commonly shared but manifested in novel ways to meet particular interactional demands.

The different data required in this study to generalize about the role of morality in talk about medicine taking therefore had to represent an “extended case” (Burawoy, 2003) in which to trace threads in the production of morality. To be considered different, it had to be based on a different set of interactional conditions to those constructed in the face-to-face interviews already undertaken. A focus group could be used to set up such a different type of interactional dynamic.

Apart from the obvious difference that using a group discussion has in contrast to a one-to-one interaction, a key strategy in setting up this alternative interactional dynamic was to share findings from the face-to-face interviews with the focus group participants. Sharing results with research participants is widely recognized as an important way to acknowledge their contributions to research projects, an essential component of knowledge transfer (Crosswaite & Curtice, 1994) as well as a powerful qualitative research tool to enhance the interpretation and validity of research findings (Lincoln & Guba, 1985, p. 373). However, such sharing is sometimes found to present difficulties

for researchers and participants (Scheper-Hughes, 2000) because the content of findings might be challenging and it might be difficult to find accessible means of communicating results to participants. The specific use of a focus group to consider findings raised dilemmas for participants in identifying with those findings, creating a different type of activity in which moral discourses of asthma management and medicine taking might be activated.

### **Focus Group Recruitment and Design**

The five ways of accounting for non-adherence, reported in Chapter Four, were:

- *Compliance as passive*. Participants with this accounting style reported monitoring their asthma and responding accordingly;
- *Minimisation repertoire using several rhetorical devices to justify medicine taking*. Participants with this style minimised the impact of asthma on everyday life;
- *Tension between lifeworld and medicine. Adherence potential threat to lifeworld*. Participants with this style constructed asthma as both interfering and as having minimal impact on everyday life;
- *Blame of healthcare breaches sick role contract*. Participants with this style blamed health care for incorrect diagnosis or treatment;
- *Minimisation repertoire using few rhetorical devices to justify medicine taking*. Participants with this style provided little or no explanation for non-adherence.

The author drew on these findings from the analysis of face-to-face interviews in designing the focus group activity. Key characteristics of four of the accounting styles found in the face-to-face interviews were used to construct four brief vignettes, each presenting statements made in the first person voice. Vignettes were deliberately constructed from the early analysis of interview data to represent each accounting style and not as specific views of individual participants. Presenting each vignette provided a basis for participants to position themselves in relation to the person represented in each vignette. All vignettes are set out in full as follows:

*Vignette 1*. Medications are necessary to control my asthma but I don't rely on them. I decide for myself whether I need to take a particular medication. Some

people use medication for the sake of it and are dependent on it. I assess how I feel and then take the necessary action.

*Vignette 2.* I do not have proper asthma. I have very few breathing problems and the brown inhaler doesn't make any difference to the way I feel. I don't have any concerns about taking medication but I often forget to do so.

*Vignette 3.* Asthma is a nuisance, an inconvenience, but it doesn't interfere with my life. I use my blue inhaler to stay in control of my asthma and I avoid situations that affect my breathing. I should take the brown inhaler every day and it is my fault that I haven't, but I don't want to be hooked on too many medications.

*Vignette 4.* I don't think I have asthma. I think doctors and nurses do not understand my symptoms and I don't feel that they listen when I go to see them or talk about the causes of asthma properly. I am concerned about the side effects of medications. The experts say that some medications are now unsafe, so I don't want to take a medication every day that I don't think works very well.

At least one person linked to each accounting style identified in the face-to-face interviews was invited to attend the focus group. Within the wider sample available, the first author made an active attempt to invite a balance of men and women, and people with a range of ages and social backgrounds. Ten people agreed to take part, four of whom later stated they were unable to attend and one further participant did not attend on the day. One other person who had not taken part in the study attended because he was accompanying his father, and he was then invited to participate. The inclusion of this participant created a particular interactional dynamic in that he was the only focus group participant who could contribute to the discussion without having the issue of potentially being represented in the vignette descriptions. The discursive methodology adopted in this study meant that this participant's talk could be analysed using the same assumption that was applied to the talk of other participants. This was that moral discourses of illness management are likely to be manifested and circulated to text and talk in a variety of social spaces involving a range of different people. This participant could therefore be included in the focus group discussion because his talk would offer an opportunity for the author to analyse a potentially different orientation to moral issues of illness management than that provided by the other focus group members. Analysing the contributions of an individual whose medical background was not known

to the author and who also had no direct connection with the vignettes presented, would be potentially fruitful if any discursive variation or tension between himself and the other participants was identified within the focus group discussion. All participants were White British, lived in Norfolk, England, and spoke English as a first language. Participants were aged between 40 and 80 years old. Five of the six participants were men.

### **Methodological Assumptions**

Using a focus group for triangulation to contextualise the production of talk on medicine taking called for this form of data collection to be managed using assumptions different from those often adopted. Although there is an increasing engagement with the variability of talk in focus groups (Clavering & McLaughlin, 2007; Puchta & Potter, 2004), researchers frequently see individual contributions and group dynamics as reflecting participants' underlying attitudes and values (Kitzinger, 1994; Redmond & Parrish, 2008). The discursive psychological approach used in this study meant that contributions in the focus group were viewed as open to change and therefore not as contributions that could be easily categorized in terms of underlying attitudes.

The task of validating findings through data sharing in this study was therefore viewed differently than research approaches that treat talk as reflecting individuals' inner realities. Individual member checking is a commonly used technique, for instance in phenomenological or grounded theory approaches, to validate research findings from face-to-face interviews by checking the researcher's interpretations individually with participants (Bloor, 1997, p. 41; Lincoln & Guba, 1985, pp. 373-378; Seale, 1999, pp. 63-72). Participants are typically asked to directly report on whether they agree or disagree with the researcher's interpretation of their interview. Any disagreements identified in this way might then lead to a reinterpretation of that data. However, using such an approach to validate individual interviews in the present study would raise rather than answer questions about any agreement between the two sources of data. Karnieli-Miller, Strier, and Pessach (2009) argued that the participant–researcher relationship activates important power relations, which poses difficulties for validating findings with participants. In this study, the act of member checking might also have been set within a moral discursive context in which the participants could be seen to justify themselves. Consider the following example taken from a face-to-face interview.

***Extract 14: 261284, (Frank). Interview 1, page 7, lines 16-25***

1. F: Well no, because I just thought well you know everybody's got asthma
2. and it seems such a common thing and um, quite frankly you don't feel
3. ill you know that's the thing you don't feel ill, ill as such, just the fact
4. you can't breathe. Do you see what I mean? You don't, its not like
5. you've got a cold or you've got the flu, anything like that. You haven't,
6. you, you're perfectly okay apart from the fact you can't, you, you're
7. gasping for breath so sometimes I'll feel a bit of a fraud for, for . . .

A key interpretation of this extract was that Frank was constructing the discursive object “asthma” as something that was not really an illness. This version of his asthma was crucial in justifying his lack of attendance at his local doctor's surgery. However, asking Frank whether the researcher was correct in interpreting Frank's view of his asthma as “not a proper illness” might have raised the issue not only of the accuracy of Frank's understanding of asthma but also his rights to access services to treat his asthma. This would potentially create a discursive cul-de-sac for Frank who, depending on his response, could be seen as in denial, as having distorted beliefs, as not requiring treatment or, rather, as a malingerer.

In the alternative discursive framework, sharing data for the purposes of triangulation is not just an activity in which the content of findings are confirmed or challenged by participants. It is also generating data. This process forces the researcher to consider the method by which findings are communicated and responded to by participants. In this study, it was necessary to confront the problem of how to share findings with participants in a way that did not reproduce the interactional dynamics of the face-to-face interviews.

***Interactional conditions of the interviews and focus group***

Instead of the analytical lens being focused on each individual's behaviour in interviews, using a focus group offered the chance to analyse a collective management of data that was not attributed to any single individual. As well as offering participants an opportunity to set out their own perspective on those findings presented, a focus

group was therefore used to provide a new set of data against which to analyse the prevalence of morality in talk about medicine taking. These data could then be triangulated with the analysis of face-to-face interviews. However, the reason for use of this form of triangulation in the study was not to seek confirmation in the focus group data of the accuracy of interpretations of the content of the accounting styles identified in the interview data. Instead, triangulation involved examining how the different interactional conditions produced different kinds of talk influenced by moral discourses. As with the interview data, within a discursive psychological framework, validation was achieved by examining “participants’ orientation” (Potter & Wetherell, 1987) to different moral discourses. The focus group data could therefore be treated as analytically additional because members were participating in an activity that was not only different, but was based on interactional conditions differing from the face-to-face interviews, requiring a different kind of participant orientation to the talk taking place. Instead of being confined within the demands of individual face-to-face engagement as with an interview, focus group participants had more freedom to stay silent and also to respond to participants other than the moderator; no set of questions was to be directed at any one person, and the author, who also acted as the focus group moderator, was primarily to act as observer rather than interviewer.

### *Issues in using a focus group to share findings*

A series of extracts selected from the transcript of the data-sharing focus group are used here to explicate specific considerations that had to be attended to when analysing this type of focus group from a DP perspective. The transcription conventions that were applied to the interview data were also used here, adapted from conversation analytic conventions to enable close scrutiny of talk in interaction. The extracts illustrate the different ways in which participants responded to and discussed the vignettes, medications, and medicine taking, underlining both the variation in participants’ responses and the different discursive strategies they adopted as a group. These examples illustrate the range of ways participants orientated to issues of morality and medicine taking within this research setting and emphasise the issues that had to be considered in analysing the data. The first consideration was what strategies the focus group moderator could adopt to construct a different interactional dynamic from the face-to-face interviews and what evidence in the data might indicate that this had been achieved. The second arose from examining what types of issues participants could be



seen to manage within this different research setting and with this task. Answers to these questions were needed to show ways in which this was a new dataset and so could support a broader examination of the role of moral discourses in talk about medicine taking.

### **Constructing an Interactional Dynamic in the Focus Group**

A key issue for constructing an interactional dynamic that differed from that generated in face-to-face interviews was linked to the moderator's role in the focus group discussion. In British media representations, researchers are commonly conceptualized either as people with clipboards on high streets asking a series of questions or as people who work in laboratories. The use of face-to-face interviews that preceded the focus group potentially reinforced the former conceptualization. In the context of the focus group, therefore, a key task was to redefine any such notions of what researchers do. This was done by the moderator informing participants on arrival that

What we will be doing in today's group will be to have a good discussion and to get your reactions, as a group of people who may well have some differing views, to some of the findings from the first interviews. The materials I will be showing you are sets of opinions that different people may make. They have no names attached and are not taken from any one interview. They have been put together from my own interpretations after I closely examined the different ways that people in interviews talked about their asthma. This is a chance to talk about what you think. (Murdoch et al., 2010)

Before they discussed any vignettes, the moderator asked participants to jot down on paper their ideas of a healthy person and an ill person. They then shared their notes with the person sitting next to them and then with the whole group. This was done to help prepare participants both to discuss the vignettes between themselves rather than directing comments to the moderator and also for the reflexive task of comparing their own positions with those presented in each vignette. Copies of Vignette 1 were distributed to each member of the focus group to read for themselves, and the moderator also read out each vignette to clarify the content. The moderator asked the participants, "What do you think?" when presenting the vignettes and then tried to minimise his own talk from that point onward, to avoid guiding the discussion of the vignettes in any

particular way. This approach contrasts with research that also used vignettes in focus groups but where the moderator took a much more active role in facilitating the discussion (Brondani, MacEntee, Bryant, & O'Neill, 2008). The moderator minimised his talk by avoiding answering specific questions and allowing silences to be managed by participants. When the group's discussion of Vignette 1 appeared to have reached a "natural halt," the moderator then passed around and read out Vignette 2, and repeated this process until the group had discussed all four vignettes. Extract 15 demonstrates the consequences of this strategy for the interaction that followed and how participants managed the moderator's silence. The talk in this extract immediately followed the presentation of Vignette 1. In these extracts, each participant has been assigned a number. Participant 4 was the only member who did not participate in the main asthma study and qualitative interviews; he did not state whether or not he had asthma.

***Extract 15: Data-sharing focus group, page 5, line 19 to page 6, line 45***

1. Participant (P) 2: Yes that's it.
2. P6: °Yep [( . . . )]°
3. P2: [Yeah ] I I yes. I suppose some people do use medication just for the
4. sake of it but um where where you know ( . . . ) are are virtually
5. dependent on it.
6. P4: Yeah but also a lot of the medications you take you have to keep a
7. regular taking of it otherwise how do you know whether you you need
8. it or do you don't it's like taking a tablet it don't work immediately you
9. take it well it is something you got to keep taking to keep ya whatever
10. it is under control so in one respect that's ((the vignette)) wrong and in
11. another way it is right.
12. (4)
13. P6: Particularly with the preventative.
14. P4: Yeah.
15. P6: Cos you don't know whether
16. P4: No exactly.
17. P6: if that's the whether you are feeling better because you changed
18. something
19. P4: Yeah.
20. P6: rather than actually keeping the

- 21 . P4: Yeah.
- 22 . P6: keeping the medication it might be that you've you know you've taken
- 23 . the carpets out
- 24 . P4: Yeah.
- 25 . P6: or wha(h)te(h)ver
- 26 . P4: Yeah.
- 27 . P6: whatever it is or changed your job or
- 28 . P4: Yeah.
- 29 . P6: whatever but this was summed summed me up I think.
- 30 . P4: I mean that would be right with the inhalers I agree you you don't
- 31 . squirt an inhaler if you don't need it but with the tablets you've got to
- 32 . keep
- 33 . P5: Provided there's no after effects of taking the tablet after a long period
- 34 . of time if you are taking the tablet and you are not using the inhaler
- 35 . afterwards um that's quite a good solution.
- 36 . (4)
- 37 . P4: So to sum it up that's right and that's wrong ((referring to the
- 38 . vignette))
- 39 . heh heh.
- 40 . ? Mm.
- 41 . P5: Yeah.
- 42 . (7)
- 43 . P6: So your first sentence "Medications are necessary to control my
- 44 . asthma but I don't rely on them" well you do in a way.
- 45 . P4: You do don't ya because if you didn't,
- 46 . P6: If they are necessary are you relying on them?

After Participant (P) 5 had put forward his view, P4 attempted to close off the discussion of the vignette by summarizing the views of the few members who had contributed so far, a summary apparently accepted by 2 other participants. This agreed-on position was potentially a cue for the group to stay silent and await direction on how to move the discussion forward, perhaps with the moderator presenting Vignette 2. The moderator offered no response, however, and a 7-second silence followed. This silence was eventually broken by P6, who attempted again to move the discussion on. This type of interactional sequence, where a series of turns is followed by a comparatively long

silence, was repeatedly made evident throughout the discussion. As the moderator continued to refrain from filling these interactional spaces, participants were obliged to continue the discussion. This contrasts significantly with face-to-face semi-structured interviews in which it is commonly the researcher who resolves long silences with a new question.

This evidence for a different interactional dynamic, poses questions about which discourses of medicine taking can be seen as being activated within this sequence and what might this talk of participants tell us about contextualising the production of talk about medicine taking. The position taken by P4 seems to embody the medical directive that prophylactic medications should be taken regularly. Throughout the whole discussion it was only P4 who continued to return to the task of reviewing the vignettes. The use of phrases such as “you got to keep taking” (line 9) focuses medicine taking on the individual behaviour rather than the medication itself. In addition, P4 positioned the person in the vignette as both “right” and “wrong” according to notions of necessity and reliance on medication. Such positioning can be seen to set up an evaluation of the knowledge and associated actions of the speaker in this vignette, framed within a medical discourse of right and wrong attitudes and actions in asthma self-management. This discursive positioning of right and wrong behaviour and attitudes provided evidence that a moral discourse of medicine taking was being activated in the discussion and was evident in a different type of interaction from the face-to-face interviews. This new data provided in the focus group supported evidence identified previously in the face-to-face interviews that the participants in this study engaged with moral notions of illness management in their talk.

A further question arises, however, about why the other participants who, from a medical perspective, could be considered not to have taken prophylactic medications as prescribed, did not overtly resist the medical directive constructed by P4. Rather, participants appear to have worked together to collectively uphold the dominant medical position without voicing questions about its assumptions. One interpretation could be that this reflected the attitudes that participants actually held. From a DP perspective, recognizing that a moral discourse was being activated between participants entails then looking at the sequences of the interaction to identify issues seen to be at stake for speakers, and therefore to identify reasons why speakers did not resist the medical position constructed by P4.

## Interactional Dilemmas

Extract 16 demonstrates how using a focus group to triangulate with the analysis of face-to-face interviews created particular issues of interpretation for the analysis of that data. The focus of triangulation here did not concern whether participants could confirm the accuracy of the vignettes. Instead, the focus was placed on the different ways participants oriented to the vignettes and medicine taking, which emphasised how and whether moral discourses of medicine taking were active within the interaction. The task of the analyst in this case was therefore to identify phrases, syntax, metaphors, as well as other devices that demonstrated this orientation. As can be seen in Extract 16, presenting findings in this research setting raised particular types of dilemmas for participants which they were seen to have to manage in their discussion.

### *Extract 16: Data-sharing focus group, page 27, line 19 to page 28, line 26*

1. Moderator (JM): Ok this one says “I don’t think I have asthma. I think doctors
2.           and nurses do not understand my symptoms and I don’t feel that they
3.           listen when I go to see them or talk about the causes of asthma
4.           properly. I am concerned about the side effects of medications. The
5.           experts say that some medications are now unsafe so I don’t want to
6.           take a medication every day that I don’t think works very well.”
7.           (11)
8. P6: Well I feel sorry for em they
9.           (7)
10. P1: Well I was lucky when I went to see the nurse she actually suffered
11.          from asthma which was great because she knew exactly what I was
12.          talking about and what I should do and shouldn’t do and I seem to
13.          remember she said there were no side effects from the brown one but
14.          the blue one be careful with the blue one seem to remember her saying.
15.          (2)
16. P6: Oh I didn’t know tha:t.
17. P5: What is the compound difference then between the brown and the blue
18.          one?
19. P1: The bro[wn one coats]

- 20 . P6: [used to be] ventolin but it's sort of salbutamol int it.
- 21 . P1: Mm the brown one coats the lung don't it though and stop irritation
- 22 . and the blue one opens the opens the bronchial tubes up.
- 23 . (2)
- 24 . P6: Mm but the I don't know whether I was (2) completely awake at the
- 25 . time but I thought when they when they hook you on to a nebul a
- 26 . nebulizer I don't know if that has happened to any of you but you're
- 27 . getting 10 times the dose of the blue one so it really is a really is a kick
- 28 . in the system.
- 29 . P1: Mm.
- 30 . P5: Mm.
- 31 . P6: Um but that I may have got that wrong but you get the blue one you do
- 32 . have a puff on the blue one but actually when hooked on to a nebulizer
- 33 . you're actually going to get 10 times the dose um the blue one in
- 34 . theory can't be that harmful can it not your blue puffer if that's the
- 35 . case.

Vignette 4 depicted an openly critical position on medications and medical expertise. After the vignette was read out there was an 11 second pause, followed by a partial sentence from P6 to distance himself from the speaker and which conveyed pity -“Well I feel sorry for em they” - but which stopped short of continuing with the evaluation of the person. This was followed by another 7-second pause. These silences and a truncated response from P6 offered a contrast to responses to the other vignettes, which were less critical, and suggested that participants were more reluctant to articulate a view that might be seen as closely aligned with the view expressed by the person represented in the vignette. There was additional evidence for this interpretation as the sequence continued. P1 broke the silence but did not offer a direct reaction to the vignette. Instead, he referred to his own experience with the use of a story about what the nurse told him about specific drugs and their side effects.

There is plenty of evidence elsewhere of how stories serve different functions in talk about health and illness (Cornwell, 1984; Frank, 1995; Lumme-Sandt et al., 2000; Lumme-Sandt & Virtanen, 2002; Wong & Ussher, 2008). One function described by Lumme-Sandt and Virtanen (2002) in their analysis of focus group discussions of medication among older people is that stories can act as a vehicle for controversial

opinions without those opinions being attributed to the speaker. Stories can be presented as a “fact” which the speaker is “just relating” to listeners, the effect being that the message within them is upheld as “truth.” They therefore present conflict in indirect terms, transmitting arguments about a particular issue without making explicit reference claims and so are difficult to argue against. Here, the opinion was that of the nurse, and so it was presented as being distanced from P1 and projected as “fact” because it came from someone with medical expertise. It could be seen as even more authentic because the nurse had asthma herself, “which was great” (line 11).

This information seemed to create a problem for how P6 understood this medication: “Oh I didn’t know that” (line 16). However, the story of the nurse not only allowed P1 to express his own view indirectly, but it also served as a device for the rest of the group to test out their own knowledge without being held accountable for anything that might be considered inaccurate. The elongated vowel in “that,” which P6 used in response, emphasises how this was not just fresh knowledge: it was knowledge that made a significant difference to how he had been managing his asthma. In contrast to his earlier statement, which he cut short, this provided an open admission of ignorance about the dangers of the different medications. He then appeared to test out his own understanding by referencing a story of when he was “blue lighted,” how he received “ten times the dose” and so effect of the blue inhaler was minimal and should not be worried about. This alternative point of view was presented as “what happened,” thereby removing claims to truth on his own part but as a truth presented through the actions of medical experts. In addition, he refrained from making a strong assertion and challenge to the argument of P1, made with his opening line, “I don’t know whether I was completely awake at the time” (line 24) and “I may have got that wrong”(line 31). This set an alternative argument against the one presented by P1, again in an indirect way.

This evidence suggests that the speakers were managing a number of different issues between themselves in their contributions to this discussion. First, there seemed to be reluctance to openly criticise medications and health care professionals in the same way as the speaker in Vignette 4, initially emphasised by the long silences. Second, the use of stories and deference to medical expertise allowed different opinions to be aired without direct ownership. This not only avoided directly aligning speakers with the person in the vignette (and thereby implicitly criticizing the medical profession), but the

stories also acted as a vehicle for the individuals to test out their own knowledge. This hints at participants' uncertainties about the effects of medications which they were maybe not willing to express too overtly.

This example shows that using a focus group to share findings in a study investigating the role of moral discourses in talk about medicine taking can create specific interactional dilemmas for participants. P2 had an accounting style in his individual interview that closely matched the doubts about medications and health care expressed in Vignette 4, but he was silent in this sequence. Moreover, the other participants avoided direct evaluation of the vignette by discussing their own experiences and testing out their own understandings of medications.

Participants might or might not have identified with the accounting style of the person in the vignette they were asked to consider. This required additional decisions by them about whether they had anything to share with the other participants. If they did identify with the accounting style, they would position themselves both in relation to the fictitious person associated with the accounting style and also to the other research participants. Despite the moderator informing participants that the vignette was not taken from any single interview, they might have speculated about whether it was they who were being represented. These issues created a potential dilemma for any participant about how and whether to share their view of the vignette with the wider focus group. This is because such sharing would have raised the risk of their then finding they were standing alone in their view, of their knowledge and beliefs being challenged or judged, or of presenting themselves as contradictory and inconsistent from the views they had expressed in the earlier face-to-face interview.

The issues participants faced in sharing their views are likely to be seen as limiting or confounding factors when viewing member checking as a task where findings are confirmed or challenged. In this study, however, issues of personal identification (or not, in the case of P4) with data offered opportunities rather than constraints to examine how these issues were managed by participants. The analysis of Extract 16 revealed how participants could be seen to be negotiating personal accountability as the discussion proceeded. The talk of P4 was also analytically fruitful, as the absence of personal identification could be seen to function as a contrast to the other participants' discursive strategies. Evincing such negotiations offered insight into a range of ways in



which moral discourses of medicine taking were activated within this interactional setting, and how participants positioned themselves in relation to those discourses. The content of the discussion also revealed how this type of focus group presented an opportunity for participants to share their experiences of asthma in a way not available to them previously. The group's shift in topics to personal experience indicated ways in which participants both shared concerns and tested out their understanding.

In Extract 17, another device can be observed through which participants managed these dilemmas, by collectively aligning themselves to a mutually held view. Here, the moderator attempted to get Participants 2 and 3, who had so far not spoken, to voice their opinion on Vignette 4, because in their face-to-face interviews they had indicated some concerns about steroids in medications.

***Extract 17: Data-sharing focus group, page 29, line 50 to page 30, line 40***

1. JM: ((To P2 and P3, could not get eye contact)) What do other people think
2. about the statement on the "I am concerned about the side effects of
3. medications"?
4. P1: You mean in general or just asthma?
5. JM: Yeah I'm just interested in what other people think about um.
6. P2: I'm just worried heh. I don't think you well you may think about it but
7. I mean if something is doing good you don't worry much about that do
8. you what is the er if you start worrying about whatever you take you
9. [wouldn't take it would you.]
10. P4: [It's the same with everything] they tell you not to eat this not to
11. [drink that so]
12. P3: [That's right ]
13. [that's the same. ]
14. P2: [I don't think that] really.
15. Some people you know I suppose do who would think would worry
16. about it but basically I don't think um the majority of people are too
17. concerned
18. P1: Yeah but with one tablet might not but several different types of tablet
19. I mean an accumulation of tablets [( . . . ) ]
20. P2: [Oh well yeah]

- 21 . (1)  
22 . P4: Yet referring to this guy or person I mean that they don't know they  
23 . don't think they got asthma I mean well what have they got then you  
24 . know um it if you go to the doctor's with the symptoms they can  
25 . usually tell you what what you've got and what you haven't you know  
26 . to say um they don't listen to me and another.

In this extract, it is possible to see how speakers worked together to achieve an agreed-on position on the person presented in Vignette 4. P2 provided a normalizing abstraction: “if something is doing you good you don't worry much about that do you” (lines 7-8). This “normal” position on medications was then equated with all things related to health and illness by P4 with an overlapping statement: “it's the same with everything” (line 10). P3 continued to establish this truth with her own overlapped repetition: “that's right” and “that's the same.” P2 then switched back to the first person. “I don't think that really” (line 14), and restated his own position, which linked back to his opening comment on line 6, and again made an explicit claim that this was a normal position: “I don't think um the majority of people are too concerned” (lines 16-17). By adopting such a collective position in relation to the person represented in Vignette 4, concerns about medicines were attributed to only a small group of people and medicines were upheld as trustworthy. P1, who did not follow this position, seemed to represent this minority group in this extract, and his statement “yeah but with one tablet might not but several different types of tablet I mean an accumulation of tablets” (lines 18-19) posed a threat to this consensus by hinting that taking medications for a long period of time might be dangerous. However, because a consensus had already been reached between Participants 2, 4 and 3, this potential threat was largely ignored rather than directly challenged.

Despite the repeated pattern of the group predominantly upholding the medical directive on the efficacy and safety of medicines, Extract 18 depicts an abrupt shift to the disclosure of a very different perspective on asthma and medicines that the whole group then worked together to share.

***Extract 18: Data-sharing focus group, page 30, line 42 to page 31, line 36***

- 1 . P6: Is there a stigma attached to [that]

2. P4: [Yeah]
3. P6: name asthma do you think (4) >are you trying to say< admitting
4. weakness
5. if you went for a [job ]
6. P4: [Yeah.]
7. P6: interview
8. P4: Yeah.
9. P6: for instance
10. P4: Yeah.
11. P6: “Oh by the way I’ve got asthma” do you think that would actually do
12. you any harm
13. P2: Yeah.
14. P6: in your job interview.
15. P4: Yes, it’s going to go against you isn’t it.
16. P6 & P2: Yeah.
17. P4: In the majority
18. P6: Do you say “I I have a bit of shortness of breath sometimes but I can
19. cope with it.”
20. P4: Yeah.
21. P2: Mm.
22. P6: You know that doesn’t sound quite so bad.
23. P4: No.
24. P6: You say “Oh I suffer from asthma" people think
25. ALL: ((Inaudible, at least 3 people responding to P6, including P3, who I
26. think said “That happened to me the other week, yeah, that’s right
27. yeah,” all making noises of agreement.))

Lines 25-27 in this sequence are striking for the level of contribution that this topic elicited from several members of the group. The discussion was then dominated by P2’s expressing how he was continually referred to hospital with no real coherent sense of what his condition might have been, and dismay at how he had been treated. In Extract 19, these issues were pursued further in the discussion and the views of P2 were then supported by other participants. The articulation of this topic was then followed by other participants expressing their doubts about the safety of some medications.

*Extract 19: Data-sharing focus group, page 33, line 10 to page 34, line 28*

1. P2: Go through all the tests and then it's up to them the doctor will say
2. "Right at the moment it's not too bad but it will get worse" this is what
3. they said to me some years ago "It will get worse as you get older" but
4. medication will sort of keep it in check and and this is that's how it's
5. been so
6. P6: The worry is too that it might be masking some underlying problem.
7. P2: This is yes absolutely.
8. P6: So that you may well have more serious complaints but because you
9. think it is all wrapped up in the asthma think
10. P2: That's right.
11. P6: they aren't taking no notice of ya.
12. P2: No no.
13. P1: Mm.
14. P6: Whereas somebody who's healthier and suddenly had
15. P2: Yeah.
16. P6: you know lung problems
17. P2: Yeah.
18. P6: might well
19. P2: Yeah.
20. P6: be thinking about other other causes.
21. P2: Yeah.
22. P1: When you go to some hospitals they vary terrifically in the type of
23. treatment you get as well
24. ?: ((noise))
25. P1: Sometimes you're in there two seconds "Oh yeah" blah blah blah
26. another one you go there and they really go to town on you.
27. (2)
28. P6: (To P1) But you've been having, well I'm I'm picking up that you're
29. actually having, you've had quite a good discussion about that blue
30. P1: Yeah.
31. P6: um remedial inhaler there's warnings about on that that I didn't realize
32. about don't know if anybody else did but
33. P1: They are steroids aren't they or a type of steroid aren't they

- 34 . P6: Mm.
- 35 . P1: which um they always tell you
- 36 . P6: I think next time I will go I would just like to know a bit more about
- 37 . the ((P6 stopped speaking))

When compared with other extracts from the focus group, this sequence demonstrates a very different orientation to the issue of medicine taking and medicine safety. In contrast to when the group collectively upheld the “medical” position in earlier extracts and marginalized challenges to that position, discussion here articulated a series of concerns about asthma, medications, and how health care is delivered. Instead of this discussion following the presentation of a vignette however, it followed the shared expression of opinion that a stigma is attached to the diagnosis of asthma. This informed a related shared discourse to argue that accepting a diagnosis is far from a simple matter: that health care can be experienced as a patient being passively handed around different specialists without the patient really knowing what is going on; that no one was very certain about what counts as safe limits to medicine taking or what is in them; that they might mask other more serious conditions; and that the standard of care seemingly differs hugely depending on luck.

The variation in how participants oriented to the vignettes and to discussion of medicine taking highlighted in these extracts provide different types of evidence of the ways in which participants engaged with moral discourses in their talk. At some points in the talk generated in the focus group, the dilemmas encountered by participants discussing the vignettes could be seen to be resolved using diverse strategies. This was done by avoiding direct reference to the vignettes and by collectively aligning perspectives with the medical directive on medicine taking and its implications for appropriate behaviour. However, the participants could also be seen to reveal concerns about medications and to test their understanding of medications through stories. These concerns appeared to be revealed more openly the further the discussion moved away from the vignettes themselves, to display a type of orientation to medicine taking that was grounded in moral discourses from participant’s everyday lives. This shift in participants’ articulated position on the safety of medications undermines an interpretation that participants necessarily “hold” a consistent medical view on medicine taking indicated in earlier extracts. Instead, it suggests that talk about medicine taking is contextualised in the demands of the ongoing interaction taking place.

## Summary

The analysis presented in this chapter has underlined how moral discourses of medicine taking were also activated within the differently-structured focus group interaction, thus lending support to the main analytical contention that moral discourses influence how people with asthma talk about medicine taking. Deploying a focus group to share findings set up an interactional dynamic that differed from that in the face-to-face interviews, posing additional dilemmas for the previously interviewed participants around whether and how they might identify themselves with the findings presented. This was not intended as an exercise in directly confirming or refuting findings from the interview data. Instead, the purpose was to use the interview findings as a device to elicit talk about asthma management that might further indicate the role of moral discourses in that talk.

The data displayed a range of varying participant views on medications, from reproducing the medical directive to regularly take prophylactic medications to challenging the safety of medications. The inclusion of P4 was fruitful in this respect as he seemed to play a key role in activating this medical directive which needed to be managed by the other participants. In contrast to approaches that advocate member checking, a DP perspective provided a means of locating such variation in relation to changes in talk about medicine taking alongside the activation of different moral discourses between several participants. From a DP perspective, therefore, using a focus group in this study could be seen to provide fresh and interesting data that could be purposefully compared with data in earlier interviews in which participants were seen to manage issues of morality.

The insights from the analysis of the focus group transcript provided key points of contrast with the interview data in how moral discourses of medicine taking could be seen to be activated. The dynamics of the focus group represented a clear shift away from the individualistic focus within interviews where questions were directed at individuals who then were required to discuss their asthma management with the researcher. Through this new interactional dynamic the role of the researcher was arguably reconstructed from someone who was an expert on asthma to someone with a much vaguer position and background. However, there was evidence that this

reconstruction was not immediate but could be seen to emerge as the discussion proceeded. This could be seen by the way participants' responses to the vignettes reproduced a medical discourse of asthma management, while, once the main task of reviewing vignettes was addressed, the discussion shifted to more critical positions, and at the end of the whole discussion a more explicit statement suggested an important shift in positioning had occurred "we thought you were an expert" (page 37, line 9). The participants' framing of the focus group moderator as an expert on medications, their realisation that this was not the case, and their expectations of the discussion were analysed. This work can be found in Appendix D. The issue for the main research questions is how this reconstruction impacted upon the talk and how this talk can be viewed as different data to that obtained in the face-to-face interviews.

The analysis revealed that although participants may have initially framed the researcher as an expert on asthma, a moral discourse of asthma management could be seen to be activated in this interaction where participants had to undertake a different task to that required in their own face-to-face interview. Instead of participants having to respond to questions about their individual behaviour and attitudes regarding asthma management, this task provided participants with a different discursive space in which to position their "attitudes." Instead of participant views being set alongside their own medicine taking behaviour, here participants' views were positioned alongside the views of a fictitious person. The collective reproduction of a compliant medical discourse to each vignette could be seen as a response to a task which was potentially viewed by participants as a test of individual knowledge about asthma and medications. This dynamic could therefore be seen to present participants with a different dilemma from the interview data about whether to articulate statements about the function, pharmacology and efficacy of medications which may then be considered incorrect and challenged. This was therefore a different manifestation of a moral discourse of asthma management in which blame and accountability was potentially allocated for incorrect knowledge. Individual responses to the vignettes, like the talk identified in interviews, could therefore be seen as performances which were dependent on having the appropriate resources – in this case, knowledge of medications. The sequential development of the discussion, in which the moderator did not display access to these resources, revealed how his talk could also be viewed as a performance which proved to be inadequate to maintain the view that he was an expert on asthma.

The majority of the participants had the additional dilemma of identifying with the findings presented. Their apparent reluctance to discuss the vignettes could be seen as a response to this interactional condition. However, this was not the case with Participant 4 who had not participated in the face-to-face interviews. Participant 4 demonstrated a greater willingness to stick to the main task of reviewing the vignettes, (contrast the different participants' responses to the second vignette between pages 11-20). The contrast between his and the other participants' contributions may have been because he was not able share experiences of asthma or medications, thus revealing a different set of required resources to medical knowledge. However, his reproduction of the medical directive, and moral discourse on medicine taking indicated that the production of this discourse within this focus group was not only situated within the context of being a person with asthma participating within the broader asthma study. It could also be seen as a discourse that circulates different social spaces and manifests differently according to different interactional tasks.

The shift in the participants' talk from being compliant to being more critical of medicine could be seen as a result of the ongoing discussion, moving away from attending to the vignette task and which may have also been influenced by the moderator's ongoing reluctance to contribute to the discussion. There are likely to be a number of reasons for this shift to personal experiences, but even without exhaustively exploring these reasons, these data could be seen to provide types of evidence that would clearly have been unobtainable within an individual interview. The increased noise and overall level of contribution seen in Extract 18 provided an example of the group dynamic not identified elsewhere in the discussion. Instead of a few individuals taking turns, the discussion of the stigmatizing effects of being labelled with asthma elicited a higher frequency of turn-taking from more participants, culminating in several participants responding simultaneously to the negative connotations associated with the term "I suffer from asthma." This discursive variation provided a strong indication that participants shared a moral incentive to present themselves as not suffering from illness across a range of social contexts. This provided further evidence that prophylactic medicine taking is situated within lifeworld settings where a moral discourse of admitting illness will "go against you."

These discussions therefore suggested how this talk was structured by a number of moral discourses, which were seen to be activated at different points through the



sequential development of the discussion. The emergence of concerns about the safety of medications, receiving a diagnosis of asthma and accessing treatment revealed how discussions and decisions about medicine taking may be manifested differently in lifeworld settings to medical conceptualisations of asthma management. This suggests that these are important insights provided by taking a discursive approach to understand talk about medicine taking, which might enable researchers and clinicians to better understand and support people with asthma and other chronic illnesses. These issues will be examined in the discussion chapter.

## Chapter Seven

### Discussion

*I mean I feel quite comfortable taking that ((blue inhaler)) (2) and it don't seem to affect me (.) an awful lot (1). It helps (2) in a way (1) with, I mean I take that and the wife says to me (.) "you've stopped wheezing". (2) I've wheezed all my bloody life so (1) I don't even hear it (.) you know? (1) She can hear it. (.) I don't.*

(261906, Interview 1, page 13, lines 31 to 38)

The study reported in this thesis explored the discursive construction of prophylactic medicine taking for people with asthma and particularly the role of morality within this. In this chapter, the reasons for doing this are reviewed before examining how the three questions set out in Chapter One have been answered using the discursive approach to understand talk about medicine taking. The three research questions were:

- How is talk about asthma management and medicine taking constructed with people who are not taking prophylactic asthma medications as prescribed?
- What role do moral discourses play in constructions of medicine taking by people with asthma and what does this say about the objectives of asthma policies and guidelines?
- How may discourse-related insights help us understand the limitations and achievements of a discursive psychological approach in understanding talk about medicine taking?

This chapter will examine this study's contribution to knowledge of adherence to prophylactic medications. It will go on to highlight issues raised by the methodological approach underpinning the study's findings, for communicating and treating patients, as well as for conducting future research in this field. These are issues that will not have been apparent in adopting more commonly-used approaches to adherence, which have focused on the individual as the unit of analysis in explaining medicine taking behaviour. Rather than interpreting individual talk about illness management and medicine taking as a representation of an internal psychological state, the approach adopted in this study has instead led to a view of talk as a "performance" (Goffman, 1959) on the part of an individual, conditional on their having access to specific

linguistic resources drawn from their social and cultural context.

## **Review of Background to Research**

The present study was informed by a review of clinical policies and guidelines to asthma management because the objectives of these documents have influenced research on adherence and also informed decisions about appropriate asthma management in clinical practice. Key amongst these documents have been the Global Initiative for Asthma (GINA), and the British Thoracic Society (BTS), and the objectives of these organisations have been to achieve individual patient's asthma control through the use of appropriate medications. From a clinical perspective meeting these objectives has often been described as essential for reducing the "burden" of asthma on healthcare resources (Barnes et al., 1996), resulting from poor adherence to medications. Researchers have therefore attempted to identify the barriers to adherence and help clinicians and patients overcome them to meet the objectives that GINA and BTS set out.

GINA and BTS have broadly grouped a range of barriers to adherence around either practical considerations for the collection and use of medications or those factors influencing beliefs about illness, perceptions and understanding of medications and the doctor patient relationship. Factors identified by researchers which are seen as relating to individual patient's personality or cognitive characteristics in effect represent components of a model of the individual in their relationship with medications – individuals' beliefs or understandings they may hold about their medication, their fears about side-effects and their beliefs about asthma and attitude to ill-health which may influence their medicine taking. Current research on "adherence to medication" usually sees the individual patient as a subject whose views of medication, asthma and illness must be treated as fixed, if those views are to be measured and related to outcomes of adherence or non-adherence. It is also necessary that the versions of medication, asthma and illness that individuals refer to, the "objects of thought", carry fixed definitions to enable those views to be measured.

From a clinical perspective, the assumption that asthma, medications and illness are fixed objects of thought fits logically within a scientific and biomedical paradigm which

is institutionally grounded in the causes of illness and generation of medications. As it is individuals who are observed, assessed, measured, treated and reviewed in clinical settings, this assumption would also offer some logical fit with adopting an individualistic approach to how those patients view their condition, associated treatments and how they might comply or adhere to preventive therapies. However, such a paradigm will view talk about asthma, medication or illness, as a window to a decontextualised and coherent internal reality that could then be measured against an external reality and medically-defined object. As a result, perceptions that were not found to match the clinical, fixed definition of the object “asthma” for example, were frequently seen by those adopting that definition as “distorted.”

The Chapter Two review of asthma guidelines highlighted how the notion that patients have incorrect beliefs (an implicit assumption within these guidelines) will lead “patient education” to realign that perception with reality. However, other evidence which adopted a discursive, rather than individualistic, view of talk, suggested that when analysing patients’ discussions of their views about health and illness, the “attitudes” these patients articulated could be seen to change over the course of an interaction, as could their versions of the objects of health and illness that they related to those attitudes. Examining this evidence suggested that the views that people express about health and illness may be intimately connected to those objects being discussed and the nature of the discussion, in turn raising questions about the viability of attempts to pinpoint a coherent individual attitude on a particular health issue. Instead, attitudes about health and illness could be seen as a discursive manifestation of the interactional conditions in which that talk was taking place.

Other cross-disciplinary research as well as evidence from this study, also indicated ways in which individuals, in discussing an issue in which they have a stake, may engage in a range of social and moral actions through their talk. Here, instead of viewing talk about prophylactic medicine taking where, given the right conditions, the speaker would accurately articulate their beliefs, it could also be viewed as a form of moral action for presenting the speaker in specific ways. The role of morality in talk about asthma prophylactic medicine taking therefore seemed worth exploring to enrich understandings of what people with asthma are doing when they talk about medicine taking and whether in turn understanding of morality in this talk better reflects the issues that inform their everyday life decisions about their medicine taking. Such

insights might also inform understandings of how people with chronic illness more generally talk about and manage their condition.

Depicting the ontological relationship between an individual's talk, internal attitude and behaviour, predominantly used as a basis for predicting adherence, has the effect of reducing an individual patient's experience of illness to a set of isolated statements which can then be categorised as specified types of beliefs, perceptions which are then used to predict medicine taking behaviour. Identifying the apparently limited capacity of individualistic approaches to capture interactional and moral issues in talk about medicine taking raised the need to adopt a different methodology which would avoid such reductionism. The alternative methodology provided by the discursive psychological approach of Potter, Edwards and Wetherell (Edwards & Potter, 1992; Potter & Wetherell, 1987), with an assumption of interactional talk as a form of social action, appeared to offer a highly promising framework in which to try and understand what happens in talk about prophylactic medicine taking and how such talk might engage with morality.

In acknowledging the relevance of engagement with moral positions in such talk it became increasingly pertinent to explore what notions of morality might structure the talk of participants and evidence that people might engage with moral discourses of illness management within a range of social situations. Further historical evidence was required to assess how asthma and morality may have been regularly linked in talk and text about the causes and management of asthma and which might also be connected by the participants in this study in a discussion about asthma management. This would enable a path to be traced from the notions of accountability for asthma constructed within these discourses to notions of accountability constructed within the talk of participants. The tools of DP appeared to provide means for tracing such a path. Other research using a discursive approach to talk about health and illness suggested the concepts of discursive objects and interpretative repertoires might be relevant in making these connections between individual utterance and wider systemic discourse. The following discussion examines what has been learnt by using DP to understand talk about asthma management and prophylactic medicine taking.

## **The Construction of Talk about Asthma Management and Medicine taking**

The data analysed from face-to-face interviews and the data-sharing focus group demonstrated challenges to simply interpreting talk about medicine taking as accurately representing a person's internal attitude, belief or perception about their illness and how they manage it. Rather than merely describing one's asthma management, participants' talk could, rather, be seen as performing particular interactional tasks. These tasks were typically seen to be to legitimise the individual's decisions about asthma management and medicine taking, so indicating speakers attempting to manage individual notions of blame and accountability for those actions. This situated participants' talk as a mutual construction between interactors rather than as an articulation of an individual internal representation. Conceptually shifting the origins of individual talk about asthma to a social space had fundamental implications for how that talk might be analytically treated. Such talk could no longer be categorised as reflecting an "attitude" because the data demonstrated discursive properties that precluded any such interpretation. These properties were that talk about illness management and medicine taking can be viewed as rhetorical, sequentially, interactionally constructed and potentially shifting, and both historically and institutionally situated. These properties, identified in the analysis of the data, reflect and build on the discursive psychological properties of participants' talk examined in Chapter Four, which emphasised speaker's interactional dilemmas in talk which could be linked to wider moral discourses in discussions about health and illness. Following the analysis of interview data in Chapter Five the discursive psychological properties were expanded to incorporate a more detailed understanding of forms of ethnographic context which may condition the production of interactional talk about prophylactic medicine taking.

First, participants' talk could be seen to be rhetorically constructed. Separate statements in talk, which from an individualistic perspective may be categorised as discrete attitudes, perceptions or beliefs, could be seen to be interrelated to perform particular discursive tasks, typically to justify asthma management. These statements could be seen to be contextualised within certain culturally-shared explanations or settings and thus seen to be rhetorical devices deployed by participants to construct an account, to discredit alternatives and to manage tensions between these competing alternatives. Examples of such rhetorical devices, seen in the analysis of interview data in Chapter Four, included the construction of discursive objects, generalising and normalising

devices, stories, external evidence such as newspaper reports, reproducing or ironizing the voice of medicine, use of witnesses or appeals to a common consensus. These devices were seen to contribute to different types of participant explanations – interpretative repertoires, which could also be seen as versions of moral and other discourses identifiable in British society. Similar repertoires could be seen to be deployed by different participants to achieve different functions. They could serve multiple functions and in some cases could be seen to be deployed by participants simultaneously, then requiring further strategies for managing any tensions or contradictions. This evidence suggested that people with asthma, in discussing their views of asthma and medication-use, may not consistently respond to some separate, external, real and fixed object. Instead, asthma, medications and illness may also be seen as discursive objects, constructed in a variety of ways to perform particular interactional tasks. Evidence of the interactional functions of this kind of talk contradicts the construction of such talk as sets of different attitudes which would appear to bear little relationship to the meaning of such talk for the person articulating it.

Second, participants' talk could be seen to be constructed sequentially within interactions. As interactions proceeded particular issues could be seen to be made pertinent at different points within the ongoing discussion. Chapter Five provided several examples of how interactional dilemmas could be seen to emerge through the researcher's choice of topics and style of questioning and through the explanations provided by participants. Similarly, the focus group data showed how the moderator presenting the vignettes led to one type of interactional sequence, (most notably marked with extended silences), whilst participants introducing stories led to a very different type of sequence. Particular types of talk about medicine taking can therefore be seen to be constructed sequentially within interactions which means that building understanding of talk about asthma, medications or illness is as much about attending to what speakers did not say, thereby calling into question any categorisation of talk as a coherent attitude or belief.

Third, if talk about medicine taking is sequentially situated, shifts should be detectable in "attitudes" being expressed by participants towards asthma and medications. Such shifts were seen in the focus group data where individual participants' views of medications could be seen to shift from downplaying the dangers of relief and

preventive asthma treatments to expressing concerns about the effects of long-term use of those treatments. A social cognitive interpretation might be that such apparent shifts in attitudes represented unreliable and distorted data about individual attitudes, a result of group influence on the expression of individual attitudes in group situations. However, such an argument implies that there is another unbiased set of conditions in which people's attitudes might be obtained. This study has emphasised, from the review of literature through to the different data analysed in this study, that talk will always be informed by and conditioned by interactional requirements. The notion that well-designed scientific research methods can somehow minimise or bypass these influences is to ignore how talk in a social world cannot remove itself from that world but will always be situated within the social historical context in which it takes place.

Fourth, the explanations provided by participants could be seen to be historically situated. In order to provide a plausible justification of one's asthma management, participants' explanations needed to make sense within particular cultural explanations of health and illness that circulate British society today. Examples of these were provided in Chapter Four and these different explanations could be seen to be situated within moral discursive frameworks that allocated blame and accountability for the speaker's actions. Two different speakers discussing the same actions could be seen to be judged differently because of how each speaker deployed different cultural and moral discourses to position their behaviour. This evidence suggested that a particular reported medicine taking behaviour is unlikely to be uniformly categorised within interactions as either appropriate/inappropriate, correct/incorrect or responsible/irresponsible. Rather, the speaker's action may be judged according to how effectively the speaker positions that action within those moral discourses that are likely to allocate blame and accountability for that action. The range of explanations provided by speakers are likely to "make sense" differently within different social historical and interactional contexts and judged according to the plausibility of the explanations provided within that context. The delivery of an explanation or "attitude" may therefore be situated by time and place but also how that talk is interpreted and evaluated may be historically situated.

Finally, talk about medicine taking could be seen as institutionally situated, demonstrated by the analysis of deviant cases and interactional conditions. The research process was itself situated within a context of specific relevance; the larger NHS asthma



study from which these participants were recruited. Using techniques from linguistic ethnography, the role of the researcher in linking the larger study with this study, could be seen to construct specific interactional conditions influencing the talk of participants. Implementing the face-to-face “interview” method could be seen to activate institutional roles of “NHS representative”, “researcher” and “participant” and to structure participants’ talk. A range of researcher and participant presuppositions about patients’ and researcher’s identities, goals and motivations were not explicit within the interview setting but appeared to have influenced how participants understood the interaction taking place. This was evident in interactional sequences of both the interview and focus group data. Researcher attempts to obtain participant views were therefore also constrained by these interactional conditions and dependent on how participants framed that interaction. Researchers’ institutional roles are often taken for granted in research settings, with researchers often taking care to ensure participants are informed about the purpose of the research rather than the researcher’s role within that setting. Informing participants about research aims is usually undertaken to uphold ethical standards of informed consent. However, the analysis of data, reported in Chapter Five and in Appendix D, regarding the role of the focus group moderator, indicated that informing participants will not only have an ethical consequence but may, equally, inform how data will be constructed within particular parameters. These insights demonstrate that talk about illness management and medicine taking, conducted within research and healthcare settings may regulate the talk within that setting according to particular communicative expectations about how interactions “should” proceed in that setting. These expectations may not be explicit or predetermined but can be seen to emerge through the ongoing discussion. This suggested that interactions about illness management and medicine taking do not therefore provide a complete representation of one’s attitudes or illness management behaviour that is consistently reproduced in a range of contexts. Instead such discussions can be seen as a presentation of illness management in a format that the speaker considers most appropriate for the type of interaction taking place.

Talk about medicine taking within research settings can therefore not easily be categorised as a particular attitude if a speaker’s talk is viewed as a product of interactions, being rhetorically, sequentially, historically and institutionally situated. This view of talk therefore reflects much of the literature reviewed in Chapter One, particularly the analysis of “interactional dilemmas” by Radley and Billig (1996) for

people discussing their chronic illness with a “healthy, employed” researcher and Horton-Salway’s (1998) analysis of the discursive construction of ME as a struggle for authorship of an illness within a contested historical space. Certain types of interaction can be seen to give rise to certain types of talk and this suggests that the discursive properties of such talk creates difficulties in assigning fixed categorical statements to talk about medicine taking. However, this is not to say that this discursive view of talk about medicine taking is so idiosyncratic that we are unable to analyse such talk to gain understanding of the issues that influence decisions people make about medicine taking. The analysis of interview data in Chapter Four revealed how participants’ talk could be seen as simultaneously unique and shared and Birdwhistell’s analogy discussed in Chapter Two provided a useful way to conceptualise this view, discussing how the different “threads” of individual talk could be seen to form part of a larger social structure (“the rope”). Participants’ talk could be seen to be connected through the different moral discourses activated within interactions and towards which participants orientated in constructing their justifications of their medicine taking. This orientation was evident in the devices that participants’ deployed, in particular the use of discursive objects and interpretative repertoires (discussed in Chapter Four). Discursive objects here could be seen as appropriations of “fixed objects” such as asthma, medication and illness, whilst repertoires could be seen as versions of broader cultural discourses. The activation of moral discourses in participants’ talk emphasised that understanding these different discursive frameworks may not only indicate the issues that were pertinent in discussions about asthma management and medicine taking. These same discourses may also be activated in other social spaces in participant’s lifeworlds. The circulation of these different moralities to lifeworld settings, in which blame and accountability for medicine taking decisions are distributed, therefore seems critical in informing how people make decisions about their condition.

The five properties identified in the analysis of interview and focus group data has enabled knowledge about individuals’ talk about illness management and medicine taking to move beyond notions of this talk as representing internal cognitive representations. A range of interactional issues can be seen to influence the production of this type of talk and people can often be seen to orientate to a range of moral dilemmas in managing these interactions. Eliciting a person’s views and versions of their illness management and medicine taking may therefore not be a simple matter of choosing carefully worded questions, or deploying the correct data collection

instruments. The findings suggested that talk about medicine taking is constructed within a social space by contextual features that may not be directly observable within the interaction taking place, potentially involving a multitude of issues and moral dilemmas that may be shifting and negotiated as interactions proceed. “Attitudes” may therefore be unlikely to be accurately and consistently articulated within this dynamic and changing social space but instead something else may be offered which is amenable to a discursive analysis. This is talk which can be seen as a manifestation of socially circulated moral issues that may influence decisions about medicine taking in daily life. Understanding the relationship between social discourse and individual talk is therefore likely to assist with getting closer to those social and moral issues that influence individual decisions about medicine taking.

### **The Structuring of Talk about Asthma Management and Medicine taking**

The Chapter Two review of literature and the analysis of language documented within a range of sources helped theorise how abstract discourses of asthma management might structure the talk of participants. This demonstrated how links have been made throughout history between asthma and morality; highlighted how links made between asthma and morality have changed; and emphasised how discourses of asthma management have been constructed and circulated to a range of social spaces, over time and are still evident today. The sources examined included journal articles that reviewed and cited historical manuscripts; original publications representing dominant theoretical conceptualisations of asthma causation and management; published research findings reporting clinical and patient’s perspectives on asthma management; and contemporary documents outlining strategies and guidelines for the clinical management of asthma. The analysis of these data formed the basis of an argument that moral discourses of asthma management were likely to be activated by participants in their talk about medicine taking. While individuals in the early twentieth century could be seen to have to account for having asthma in the first place, more recently this connection between accountability and causation has been replaced by a connection between accountability in relation to how individuals manage their asthma and the decisions made about medications. In contemporary asthma guidelines, being accountable for one’s management of asthma symptoms, has been linked with notions of responsibility, autonomy, authority and empowerment, orientating around the central requirement of preventive control of one’s breathing.

Many participants could be seen to justify their non-adherence to prophylactic medications, so indicating how an asthma prevention discourse might structure these justifications. At the heart of this rhetorical talk were versions of the individual, their attitudes, identities and behaviour, which speakers worked to present as trustworthy and authoritative and in which their actions could be seen as reasonable and responsible. Being accountable for one's asthma outcomes could therefore also be seen as a reproduction of a moral discourse of asthma management which places clinicians and patients as the "empowered decision-makers" yet accountable for those decisions.

However, the historically-situated explanations that participants provided (see fourth property of talk discussed above) revealed notions of accountability that were constructed within other moral discourses of illness management. These discourses appeared to circulate a range of social spaces and constructed versions of doctors, patients and the doctor-patient partnership in ways which could be attributed to a variety of sources, rather than seen as a direct reproduction of asthma management discourse evident in asthma guidelines. In addition, notions of doctor's and patient's responsibility, evident in asthma guidelines can be seen to be emergent from traditional sick-role conceptualisations, and the emphasis on doctor-patient partnership within guidelines reflect broader contemporary discourses regarding the "concordant" partnership and its replacement of the traditional "compliant" doctor-patient relationships (Royal Pharmaceutical Society, 1997). The talk identified in the interview and focus group data cannot therefore be easily traced to any one particular source, nor can a range of distinct moral discourses be identified as independent entities with bounded sets of terms that speakers might deploy in their talk. Rather, something much messier happens in interactions, with speakers' explanations appearing to appeal to shared understandings that may have multiple explanatory premises, can be seen to have origins in a variety of places, and yet wholly attributable to none of them.

The indeterminacy of talk was nowhere more evident than in how the concept of "control" was deployed by participants. In all the sources examined in this study, control appeared as central: control of one's emotions, (either consciously to avoid symptoms or to express as a form of cure); of one's mind, (either as emotions and desires or as beliefs and knowledge); lifestyle and habits (from sexual activity and diet to daily decisions about medicine taking). More recently, the relative success of

prophylactic medications in preventing asthma symptoms has increasingly encouraged discourses linking control to prevention rather than control by responding to symptoms through the use of reliever inhalers. As discussed in Chapter Two, prophylactic medications have only been in wide circulation since the 1980s. It was evident that many of these participants, who, from a medical perspective, could be considered as “non-compliant” or “non-adherent”, justified their medicine taking by deploying the older discourse of symptom control. This is a discourse associated with the management of acute conditions and participants justifying the control of asthma symptoms through relief medication could often be seen to associate the use of a symptom control discourse with the discursive construction of the object asthma as “not serious”, “not debilitating” or “not proper asthma.” Much of the research reviewed in Chapter One (Halm et al., 2006; Horne & Weinman, 2002) pinpointed this “perception” of asthma as a key reason why many people do not adhere to prophylactic medications or attend their surgery and instead rely on alternative strategies. However, the analysis in the study reported here demonstrated how it may be advantageous to view these “perceptions,” not in isolation, but as connected by people with different versions of their own self, such as someone with asthma, with an acute or chronic illness, fit for work and working hard, a fraud, someone who cares and is not cared for and not a burden. These versions of the self and one’s condition can be seen not merely as “distorted perceptions” but as formulations of health problems that may play a crucial role in influencing which versions of the self people can construct and which may enable them to participate in everyday life.

The management of asthma and illness more generally may therefore extend beyond the physical experience and management of physical symptoms to a social experience of asthma and illness. This can be seen as a control not only of symptoms, but of one’s attitudes, identity(ies) and behaviour within medical and lifeworld contexts. This finding clearly resonated with the concept of “identity work” of Adams et al (1997) in which people with asthma engage, Cornwell’s finding of participants’ “public accounts” (1984) where moral implications of illness were managed, alongside other work emphasising how people with chronic illness actively construct themselves to enable participation in society (Charmaz, 1990; Frank, 1995). Notions of self-control are clearly not isolated to one aspect of health or indeed to health itself, but can be seen to be situated within other moral discourses about individual control and discipline, within which speakers actively position themselves. In his narrative analysis and discussion of

chronic illness and the pursuit of virtue in everyday life, Gareth Williams makes this connection in commenting that in 1980s British society, health, like wealth was neither good nor bad in itself. What was good was “the self-disciplined activity, which according to Protestantism and Mrs Thatcher, produces them; and in their absence is a sure sign of gluttony and sloth” (Williams, 1993, p. 92). Tracing a path between individual utterance, (regarding control or any concept implicated in moral accountability), and the moral discourses structuring such talk proved difficult because concepts such as control could be seen to originate in a variety of locations. In addition, the historically-situated individual whose talk can be seen as both regulated and productive of wider discourses added further complexity to tracing these origins.

These difficulties in determining the structuring of “attitudes” and versions of events indicates that talk about illness management is not necessarily what Fairclough referred to as “naturalised” (1995) within a particular discourse convention. As discussed in Chapter Three, Fairclough argued that particular institutional settings bring about, or “naturalise” particular discourse conventions. This was reflected in the fifth property of talk identified in this study which identified talk about medicine taking as institutionally situated. However, in contrast to Fairclough, this property highlighted that the regulation of talk was not prescriptive but could be seen as a complex arrangement of interactors’ communicative expectations of that institutional context which are difficult to determine. The discursive complexity within interactions suggests that Goffman’s term “loose coupling” (1983, p.11) between utterance and social structure appears to be a more helpful conceptualisation with speakers negotiating a number of moral discourses in their talk. However, this suggests that the discursive approach taken in this study is limited in the ability to locate talk about illness management and medicine taking within a coherent moral discursive framework that might be used to critique existing policies and inform the generation of future illness management guidelines. Instead it suggests that individual constructions of illness management and medicine taking needs to be understood for how shared understandings of illness management are manifested in talk in novel ways which might indicate specific concerns that speakers orientate towards.

However, this study has built on research that has highlighted interactional and moral dilemmas in talk about health and illness by identifying how blame and accountability might be differently allocated according to the interactional conditions of different

encounters. What was said within interactions could be seen not only to be influenced by the talk taking place but also by how the research setting and those interacting within it were constructed prior to that encounter. Adopting an approach through which to take account of the interactional conditions in which illness talk and medicine taking takes place may therefore enable understandings of which moral discourses are likely to be activated, how these discourses might structure those interactions and to offer means of examining them. This in turn may provide firmer understandings of how speaker's constructions of concepts such as control may be evaluated and categorised. This therefore re-emphasises how talk about illness management and medicine taking can be viewed as a performance in which speakers must deploy appropriate linguistic resources in order to be categorised in what they and other participants may see as appropriate ways. These "appropriate categorisations" can be seen as discursive objects that have emerged from different moral discourses, such as: the responsible manager of one's health; compliant patient; empowered decision-maker; in control; and hard-worker. The findings suggested that being categorised in these ways will enable access to particular types of outcomes regarding the clinical management of symptoms, or activities within lifeworld settings such as work. Understanding how talk about medicine taking operates as a performance therefore provides insight into the process by which people living with chronic illness might come to be categorised within consultations and lifeworld settings, how relevant these categorisations might be for how they manage their condition and the consequences of these categorisations for treatment decisions.

### **Talk as a Performance**

The discursive psychological and linguistic ethnographic methodological framework used in this study enabled talk to be situated and linked to wider moral discourses of behaviour. However, it also demonstrated how talk about medicine taking may be a continuously constructed performance within interactions. Participants could be seen to shift the orientation of their talk to meet the specific discursive demands that they evaluated as relevant at particular moments within interactions. From a medical perspective that deploys a discourse of prevention and adherence in understanding patients with asthma, it is possible to argue that some explanations of asthma management may be interpreted very differently to others, with different consequences for those people. The interview data analysed in Chapters Four and Five illustrated a range of ways participants' accounted for the same kinds of medicine taking behaviour,

or “non-adherence”. These different versions could be seen to be historically situated with varying degrees of blame attributable to individual speakers. This analytical work indicated that people, in discussing how they manage their condition, are potentially categorised according to the effectiveness of their rhetorical accounts rather than how they actually manage their condition in everyday life. Rather than participant’s “attitudes” and medicine taking behaviour, it may be their linguistic performance within the interaction that is categorised by the researcher, doctor, nurse, according to the criteria that are set up within that interaction.

How these criteria are communicated to patients or research participants appeared in this study to be critical in the consequences for the interaction that takes place. The institutional roles, presuppositions about those roles, normative expectations about the type of interaction taking place as well as the ethnographic contextual features are likely to have some bearing on how interactors understand, or “frame” those interactions and therefore the perceived criteria used in interpreting the talk within it. People with chronic illness will engage with the framing that they feel is relevant for that particular interaction and how they want to be understood - according to that framing. The variations in talk according to particular framings was made evident through the analysis of interviews where a few participants did not appear to frame the research interview as one where a narrative was expected and one in which the participant’s identities had previously been constructed in particular ways – as a “person inadequate control and quality of life” and “person non-adherent with medical care.” The apparent lack of access, or use of these resources potentially contributed to a very different type of interaction as a result, seen in the analysis of extracts in Chapter Five. The lack of display and apparent access to particular resources in these extracts indicated that it was these participants’ performances that were categorised and not how they actually engaged with their condition.

This view of the performative elements of illness narratives builds on work undertaken already on how people provide stories within research interviews, (Bury, 2001; Riessman, 2003a, pp. 340-343), and clearly linking with the work of Radley and Billig and their concept of “interactional dilemmas” (1996) faced by people with chronic illness in presenting themselves as healthy and fit for work. Skultans (2000, p. 9) argued that “narrative makes actions intelligible to the self and to others by showing the part they play within an intentional project.” These “intentional projects” seen throughout



much of the interview data in this study have indicated a manifestation of issues that may also be performed in dealings with people in lifeworld settings, reflected closely with studies that have also demonstrated the performance of illness in everyday life, such as the experiences of patients with arthritis (Bury, 1988, p. 92); patients with traumatic spinal cord injury (Yoshida, 1993); and narratives produced within clinical care, referred to by Mattingly as “healing dramas” (2004, pp. 73-94).

However, the concept of performance developed from this study’s findings has the closest connections with Riessman’s (2003b) analysis of performance narratives for men with multiple sclerosis. Using a similar analytical approach to this study, Riesmann used the theories of Bourdieu and Goffman to examine two contrasting performances of masculinity, situating these accounts within a social historical and interactional context in which the social structures of gender, class and disability could be seen to structure and be reinvented in accounts of the body and social space. Like Riesmann, the findings in this study emphasise a dynamic relationship between social structure and individual agency in performances about illness management and medicine taking, in particular how the same condition or behaviour may be constructed and therefore construed very differently depending on how it is historically and institutionally situated.

Yet the research on performance narratives typically bounds that talk within the interactional context taking place. Other research within health (Roberts et al., 2005) and outside of health (Billings, 2009, September; Blommaert, 2005; Mehan, 1996) has shown the importance of accounting for the distribution of linguistic resources and their transference across contexts in how talk and therefore “performances” are interpreted within different interactional encounters. This study’s findings combines insights regarding the performance of talk and the allocation of linguistic resources, within the field of medicine taking and talk about illness management. Understanding how talk about illness management can be seen as a performance where speakers’ linguistic resources are evaluated against specific criteria enables us to interpret the role and functions of power and the dominance or absence of particular discourses in talk within research and healthcare interactions. Because illness management and medicine taking can be viewed as a social and not just physical experience, people, in discussions with clinicians or researchers, may orientate to a number of moral discourses in talk about medicine taking. However, the crucial point for how people are viewed within health care interactions, and how those discussions proceed, is which versions of illness

management and medicine taking clinicians are attending to in those interactions and what criteria will be used to categorise the performances that people with asthma or other chronic illnesses are displaying. Unlike Goffman's use of the term "performance", (which carried the implicit assumption that interactors had a shared understanding of the meaning of the performance which took place), the success of these performances is likely to depend on the distribution of resources within interactions, which may not be shared between clinician/researcher and patient/participant. The meaning of these performances is also likely to be fluid, as cultural meanings of different health behaviours and display of symptoms have been shown, in this study (Chapter Two and Appendix D) and elsewhere, to be regulated, negotiated and resisted across space and through time (Brandt & Rozin, 1997; Herzlich & Pierret, 1987; Sontag, 1991), manifesting itself through policy, guidelines, health promotion initiatives and media images (Davison, Davey-Smith, & Frankel, 1991), clinical practice (Pollock, 2005), interactions about health and produced by individuals in their talk (Pill & Stott, 1982). The interpretative repertoires that people construct within discussions about their illness management may closely match contemporary, localised discourse that may be key in allocating blame and accountability, or perhaps refer to more out-dated, remote discourses that are limited in their functional effectiveness within the interaction taking place. Inequalities in access to resources within health interactions may therefore result in clinicians or researchers inappropriately categorising a person's engagement with their condition on the basis of "information about attitude" they see as having been given in their discussions with that person. The "wrong" kind of patient performance, i.e. one's that are considered incorrect from a medical perspective, may lead to clinician accusations of the patient being irresponsible, non-adherent, having the wrong beliefs or being in denial. Inappropriate categorisations therefore have the potential to lead to inappropriate treatments being prescribed, a view which is reflected in research that has shown the potential detrimental effects of a medical agenda controlling consultations and marginalising patients' lifeworlds in those discussions (Barry et al., 2000; Mishler, 1984).

Asthma or other illness prevention discourses are perhaps only available to people whose backgrounds have equipped them with the linguistic resources required to enable a discussion that will be effective within the institutional framework of medicine. This is not the same as saying that education is the key to improvements in adherence. What it means is that because of socio-economic and socio-historical circumstances there are

inequalities in access to these resources that means that some people will be more effective at accounting for their behaviour than others, whilst not necessarily any more likely to be “adherent.” This point is echoed by Roberts et al (2004) who have shown that people’s abilities to utilise institutional, linguistic and bureaucratic resources within consultations is a growing problem in areas of the UK with increasingly diverse populations, having consequences for how consultations proceed and potentially treatment outcomes.

People with chronic illnesses may become delineated within the discourse of prevention according to clinical and researcher’s assessment of their “beliefs.” The effectiveness of the articulation of those beliefs within an interaction about symptom prevention may determine the particular subject position that clinicians/researchers “assign” to patients/participants within that framework. Moreover, people with chronic illnesses may not make decisions about how they manage their condition based on subject positions within this discourse and are unlikely to make the judgement about how their illness management is positioned within it. The tensions that were manifested in eliciting participants’ “attitudes” and versions of their medicine taking behaviour within the interviews of this study may be seen as transferable to healthcare interactions more widely both at an interactional level in relation to access to resources and also at a moral discursive level, in relation to the basis on which decisions about illness management are made.

### **Interpretations of Talk and Decisions about Prophylactic-Medicine taking**

If we view interactional talk about medicine taking as a continuously-constructed performance then it is difficult to determine from that talk how people with chronic illness make decisions about medicine taking in everyday life. However, the literature review, which included an examination of the language within asthma guidelines, the analysis of interview and focus group data provided different types of evidence of how discursive links have been made between asthma management and morality and that these links could be seen to be circulated and manifested within varied social spaces. In *asthma guidelines*, discursive links could be seen in the incompatibility of an ideology of patient-centred medicine with policy directives that regulate the options available to clinicians and patients. This tension has the potential to radicalise clinical decisions which do not conform to the guidelines and so imposing a moral incentive for clinicians

to comply with orthodox treatment recommendations. *In the interview data*, the majority of participants could be seen to be preoccupied with providing plausible reasons for the decisions they reported. These reasons were rhetorically constructed using different culturally-available discursive objects and interpretative repertoires in their talk such as the sick individual passively filling up with tablets or versions of the hard-worker. These rhetorical constructions may be particularly effective in allowing these people to function in important social networks and lifeworld settings that they access in everyday life. *The focus group data* by contrast displayed evidence of some participants' reluctance to identify with a position running counter to an orthodox medical directive on medicine taking. Such reluctance demonstrated an awareness of the authoritative medical discourse on the correct function and use of medicines, a discourse to which participants may feel required to respond and to position themselves in morally acceptable ways.

When people talk about illness management and medicine taking they may (as shown in Chapters Four and Six) orientate their talk to multiple moral discourses that have some connection with that talk. Blame and accountability can be seen to be allocated differently according to the performance of that talk within the particular moral discourses that are activated within interactions. This suggests that talk about illness management will function differently in different interactional contexts and therefore may be indicative of the moral discourses in which people make decisions about medicine taking on a daily basis. While a medical discourse of asthma management may classify a particular attitude or behaviour as "incorrect" or "non-compliant"; within alternative lifeworld discourses, these same attitudes and behaviours may be considered appropriate and normal, and function to uphold important lifeworld identities. The explanations provided by many participants, indicated that taking relief medications lay at the heart of these alternative moral frameworks where blame and accountability were distributed. "Non-compliance" or "non-adherence" to medications, attendance at a local surgery or to any aspect of healthcare could, in many lifeworld contexts, therefore be seen as an appropriate response.

Situating individual's talk within a lifeworld context reconfigures our understanding of how decisions are made about illness management and medicine taking. Instead of locating the individual as having a package of attitudes and beliefs which can be elicited and measured to predict adherence to prophylactic medications, without reflecting on

the construction of those attitudes, a more holistic understanding of the individual is made available. This is to more fully appreciate the individual's management of illness at a unique intersection of the other influences in their lives. These influences are not discrete entities but form a complex arrangement of concerns into which "having asthma" or any other illness has to fit if those people's lives are to be maintained. This understanding resonates with other work which has emphasised that illness and its management needs to be viewed as a social and not just as a physical experience in which people actively construct their identities in order to participate in social life (Bury, 2001; Charmaz, 1983; Frank, 1995). This study has emphasised that dimension of this experience which relates to the individual body experiencing a physical condition within a range of shifting moral discursive contexts. Medicine taking then, can be positioned as a social activity that interacts with other social activities which situate medicine taking with a range of moral connotations, defining individuals in their use of those medicines. It has therefore been argued that to understand decisions about medicine taking we need to view this social activity alongside other such social activities and alongside how the individual is positioned within moral discourses associated with those contexts. This approach situates the unit of analysis outside the individual and within their lifeworld context in which decisions are made and discursively managed, while considering that individual's social and moral activities. This evidence provides insight into and considers the compatibility of available and efficacious treatments with patient's lifeworlds, before the compatibility of individuals' beliefs with clinical treatments. This may provide more convincing explanations of patients' practices in relation to adherence than can be provided by individual attitudes to medical objects.

In this study, differing discursive contexts were identified in which moral discourses of medicine taking could be seen to be activated, and also likely to be activated between clinicians and patients in consultations about asthma and other chronic illness management. The value of educating patients about medications can, in this way, be seen as too limited in the ability to influence how people will use those medications. This is because here the relevant issue for patients can be seen not as one of whether patients understand their condition, what medications do and the need for adherence but, rather, as what these may mean as concerns in people's everyday lives. One application of the ideas examined here may therefore be to find ways to help attune clinicians to the

moral dimensions of talk being attended to and to respond accordingly in communicating with patients.

### **Some Implications for Communicating with Patients in Clinical Settings**

Within the discourse of adherence, people with chronic illnesses may become designated as “good patients”, “bad patients”, “responsible”, “irresponsible”, as having “accurate understanding” or “incorrect beliefs“, as “compliant“ or “non-compliant”. Such adherence discourse-related designations may be based on clinical judgements of the effectiveness of their talk within an interaction according to particular criteria of disease control and associated recommendations for appropriate illness management. Peoples’ performance of that talk may affect how they are assigned within that framework, with likely consequences for the treatment decisions reached by clinicians, with patients potentially being prescribed medications they may not have wanted.

Viewed in this way, through a discursive psychological and linguistic ethnographic approach, the function of treatment guidelines may need to be repositioned as a reference point rather than a recommendation for treatment. If notions of the individual need to be re-located within a moral discursive context, so, too, do notions of evidence and patient and clinical expertise within a clinical setting. Instead of attempting to reconcile the inherent contradictions between clinical, evidence-based and patient-centred practice, the clinical encounter could deploy a broader notion of evidence than a medical paradigm that upholds randomised controlled trials as the gold standard to inform practice. This evidence would be provided by the patient, but instead of focusing only on their talk as a means of assessing the accuracy of patient’s beliefs, this view would understand such talk as indications of the dilemmas and issues at stake for patients.

The alternative or additive interpretation offered here would have implications for how the consultation may proceed. For example, a patient with asthma reporting that they only used a brown prophylactic inhaler when they felt that they were getting a cold might lead to the consultation proceeding in one of two distinct ways. A discussion that conformed to asthma guidelines might follow whereby the nurse or doctor educates the patient about how their asthma is a continuous underlying condition that needs daily management, and that in order for the brown inhaler to have any effect the patient needs

to take it much sooner before any cold symptoms arise. This would be likely to bound the discussion within a medical discourse of asthma management and so close off opportunities for the patient to express the role of medications in their everyday life. However, when repositioning evidence within patients' everyday lives, the clinician might instead ask the patient whether they are concerned about taking a medication everyday. This might lead to a discussion of medicine-use in a lifeworld context, in which particular moral discourses circulate, which may then facilitate further discussion of the compatibility of a prophylaxis within those settings. The need to facilitate discussion of patient's concerns about medications has already been highlighted in research that has shown the difficulties patients experience in articulating concerns about medications (Stevenson, Barry et al., 2000). Within this view, the clinician's role as expert would therefore be less about advising patients about what they "should" be doing but rather as being able to offer a treatment that best meets the patient's concerns and needs. This is not to say that patients become "empowered decision makers", and that clinical consultations may be more "concordant". There is evidence to suggest that some people do not wish or expect to be given a choice in their treatment (Butler, Rollnick, Pill, Maggs-Rapport, & Stott, 1998; Makoul, Arntson, & Schofield, 1995). Rather, discussions about illness management need to be repositioned so that decisions are more fully informed by the issues that are pertinent to patients in everyday life. The patient's expertise does not lie in providing the solution however, but lies in their experiences of the issues that affect their participation in activities such as work, school or other social activities.

Instead of viewing evidence as an objective object against which to measure patients' attitudes towards treatment or illness, this sort of evidence varies according to the moral discursive contexts of patients' lives. Instead of viewing talk as a separate entity from evidence and assessed as either correct or incorrect, such talk might be seen as providing the evidence itself and so avoids any inherent contradictions between clinical and patient perspectives. The notion of doctor-patient collaboration might therefore also be reconfigured. Instead of attempting to persuade patients to adhere through different tactics, using what Habermas called "open" or "concealed strategic action" (Scambler & Britten, 2001) this approach is about accepting how and whether medications are compatible within people's lives and the function that "non-adherence" might play in lifeworld contexts – an approach which Habermas referred to as "communicative action". Reframing both ideas of evidence and talk in this way may help reduce

clinician and patient time and service resources spent “re-educating” patients to little effect and only to repeat such discussions at a later date.

### **Limitations and Achievements of a Discursive Psychological Approach to Understand Talk about Medicine Taking**

This study has been able to provide novel insights into the production of talk about prophylactic medicine taking in moving beyond individualistic approaches undertaken to date to explain and predict adherence to prophylactic medications. However, the predominantly discursive psychological methodology used in this study does not provide an alternative means of obtaining patient perspectives in order to better persuade those patients to take prophylactic medications more regularly. Rather, it reconfigures our viewpoint of the individual person with a chronic illness and the role of medications within that framework. This is one in which the individual is located within a range of interacting social spaces. Medications and medicine-use are then assessed as to whether it is compatible with those spaces. This study has attempted to understand this by shifting the unit of analysis away from individualistic, attitudinal concepts to a study of interactional issues within a social space.

The interview and focus group methods deployed to understand the discursive construction of participants’ talk created social interactions in which the language of medicine taking would be reproduced and produced through the interaction. However, these were not “real-life”, or naturally occurring interactions, but, as the analysis in Chapter Five brought out clearly, were unusual encounters for discussing asthma management, with vague definitions, boundaries, roles and expectations. The construction of the research settings and data within this study will therefore have produced a particular type of talk and resulting data. Although examining the contextual conditions in which participants were recruited and interviewed provided valuable insights on the production of this study’s data, the methods used in this study restricted the analysis largely to linguistic techniques, precluding a broader understanding of participants’ naturally-occurring language as produced within the social spaces in which asthma was managed. This potentially limited the kinds of moral discourses that would have been activated within interactions which would reveal the moral concerns of participants that might influence daily decisions about medicine taking. These limitations were initially identified from analysing the interview data and were



addressed with the use of the data-sharing focus group. Whilst this focus group can also be viewed as an unusual encounter for participants to discuss asthma and medications, the researcher set up the group to help facilitate other kinds of moral discourses that might be activated in this different interactional dynamic. The groups' shared concerns about being a person labelled with asthma, of long-term medication use and experiences of healthcare suggested that using the focus group was successful in activating different discourses to the face-to-face interviews. It also demonstrated that further, potentially richer insights regarding the link between moral discourses and medicine taking might have been identified by observing discussions of asthma in participants' lifeworld settings.

However, the purpose of this study was to explore the value of investigating talk about medicine taking using a discursive methodology, an alternative approach to those that have viewed this talk as representing individual attitudes. This study has achieved this aim by pinpointing key properties in participants' talk and showing how this talk can be seen as both structured and creative of moral discourses. By adopting a discursive psychological and linguistic ethnographic methodology we might now better understand talk about medicine taking as a performance, subject to differing linguistic resources and as a manifestation of moral issues that inform daily decisions about medicine taking. Interview and focus group methods provided appropriate means for examining this because they provided opportunities to elicit such talk in direct conversations with participants. Discursive psychological analytical techniques provided the tools to analyse the discursive construction of participants' talk and using these tools highlighted the interactional dilemmas that people may face in discussing how they manage their condition. Additionally, interpreting interview data was enhanced by using techniques and ideas from linguistic ethnography to allow a more explicit and detailed examination of the exercise of power in context.

This study has therefore provided a foundation on which to build a more sophisticated methodology to further examine the relationship between talk and illness management. Such examination might focus on how performances relating to illness management are seen to play out in everyday settings or to understand the positioning of medicine taking as an activity alongside other social activities. A methodology to understand these issues might combine linguistic and ethnographic approaches and could be implemented using a form of participant observation to identify what sorts of interactional dilemmas

and moral discourses are activated when people need to manage their conditions within lifeworld settings. These insights would provide further evidence of how illness management and medicine taking are positioned within people's everyday lives and suggest new ways in which people might be supported to manage their conditions within these contexts.

In deploying a discursive psychological and linguistic ethnographic approach to understand talk about medicine taking, the findings of this study also raised other potentially important issues which were not possible to pursue within the scope of this project. Firstly, the approach taken in this study could have led to a more detailed analysis of how different types of talk could be seen to be dominating or be marginalised in discussions of asthma management. The discursive variation identified in the analysis of focus group data regarding participants' "views" of medications indicated that medical conceptualisations of medicine taking functioned at certain points to marginalise competing alternatives regarding the safety of medicines. In contrast, the analysis of interview data provided examples of how participants constructed versions of themselves whilst at the same time undermining and marginalising less-desirable alternatives. It might therefore have been fruitful to explore further how and when medical versions of asthma and illness management could be seen to dominate participants' talk and therefore the implications of this for what may be left unsaid in discussions about illness management and medicine taking.

Secondly, the consideration of the circumstances in which participants' justified their medicine taking led to the concepts of "affordance" and "discursive space," building on Radley's (1993) analysis of agency and "spaces of action" in how people live with and talk about chronic illness. Radley discussed how spaces of action are available to people with illness between what is expected regarding their behaviour and what can be attained. Appendix D includes a comparison of the rhetoric identified within two extracts selected from one interview undertaken in this study. This brief analysis indicated that it would be fruitful to further explore examples of variations in the "affordance" of "discursive space" to understand how individual choice might be positioned within different moral discursive frameworks. Justifying illness management may be related not only to the activation of different moral discourses within interactions (and speaker's access to those discourses) but also to the discursive space that is afforded within ongoing discussions.

Finally, the biographies that were provided by participants regarding the origins of their asthma, the circumstances that led to a diagnosis and then use of medications could have been explored in more depth. These stories could sometimes be seen to contextualise the version of asthma that the participant constructed within interactions, which was then used in justifying the decisions that they had made about the use of prophylactic medications. In a similar fashion to the work undertaken by Horton-Salway and her analysis of talk about ME, stories about the origins of asthma could have been analysed for how and whether participants “struggled for authorship” (Horton-Salway, 1998) of their condition. This may have offered insight into how blame and accountability may have been pertinent in discussions of the causes of asthma, offering points of contrast to discussions regarding the management of asthma.

### **Summary**

The findings from this study have provided an important contribution to the existing body of knowledge on medicine taking and particularly knowledge about prophylactic medicine taking for people with chronic illnesses. The findings have indicated that attempting to identify individual attitudes or beliefs about illness or medication as a technique to improve how people take medications is inadequate in identifying the best ways to support people with chronic illness. They have also provided insights into why attempting to improve peoples’ adherence to medications solely through educational techniques is likely to have limited success. In addition to providing a critique of current asthma management strategies and research aimed at improving adherence, the findings have suggested that a more useful way of understanding how people talk and make decisions about medicine taking might be found using discursive and ethnographic methodologies. The approach taken in this study has provided insights that indicate a range of contextual features influencing individuals’ talk about illness management within interactions and understanding what influences individual decisions about medicine taking may involve taking account of these features. Key amongst these are likely to be a range of culturally-available moral discourses of illness management that can be seen to circulate medical and lifeworld contexts. Individuals’ decisions about taking medicines may therefore need to be seen in terms of how it is evaluated within those contexts and whether it enables those individuals to participate in important social activities. Other contextual features influencing talk could be seen to be produced

through the researcher's role and implementation of the study design. The choice of methods could have been improved by incorporating observational data of everyday interactions about asthma management which would have provided better understanding of the interactional issues and moral discourses that might have more direct influence on participants' daily management of asthma. However, the interview and focus group data helped illustrate how people's talk about medicine taking can be viewed as a performance. This insight suggested that individuals' ability to utilise specific linguistic resources within interactions may be key in how performances are categorised by other members of that interaction, having important implications for how healthcare interactions are conducted. The methodology used in this study provides a means of understanding how talk about medicine taking is constructed within interactions which might then be used to communicate more effectively with patients but also to better understand the issues that inform daily decisions about medicine taking.

## Chapter Eight

### Conclusion

*They've always got a weapon (1) like weight, smoking, (1) and something else (1) it could be em, (1) excuses as to why (2) you'd suffer less if you were (2) perfect. (2) Which we ain't none of us, are we? (1) That's how I feel and so (.) sometimes I'm reluctant to go because of that. (1) That is the truth.*

(121221, interview 2, page 24, lines 46 to 51)

The contribution of the findings reported here is in providing a novel way of conceptualising how individuals talk and make decisions about medicine taking, with substantial implications for communicating with and supporting these people in managing their condition. Whereas health education approaches have assumed that individual attitudes can be elicited from patients, measured and then used as a means to improve adherence to prophylactic medications, the new conceptualisation offered in this study views the individual within a social and moral historical context which is multi-dimensional and shifting. Here, talk about illness management is seen as a form of social action and a product of a dynamic relationship between social conditions and the individuals within interactions, and to be both structured and productive of moral discourses of asthma, illness management and medicine taking. Medicine taking can also be viewed as situated within different moral contexts and the decisions that people make as social acts defined by these contexts. This final chapter will summarise the key insights that have led to this conceptualisation, underline its contribution to knowledge, and suggest further related research and implications for improving the clinical care of patients with asthma and other chronic illnesses.

The novel conceptualisation of how individuals talk about and take medications, which emerges from the findings of this study, arose from adopting a fundamentally different understanding of talk about asthma from previous research about adherence to prophylactic asthma medications. Instead of viewing individuals' talk about asthma or medications as an articulation of an internal representation, talk was viewed as a product of interactions within a social historical context. The primary data collected in this study was obtained from transcribed face-to-face interview and focus group data which was

then analysed using discursive psychological and linguistic ethnographic approaches. The language within a range of other data sources was also examined to see how people with asthma were constructed in relation to the causes and management of this condition. In addition, non-textual forms of data were examined in relation to how the researcher, participants and interviews were constructed within this study. This was therefore a study of language and its use, and its view of the individual, as situated and defined by context, represented a significant departure from previous individualistic approaches to adherence which have identified the individual owning and expressing coherent and bounded attitudes and beliefs distinct from context.

Shifting the core unit of analysis from the individual to their situated language therefore enabled access to a new form of knowledge about asthma medicine taking. Instead of producing an epistemology of the individual and their attitudes or beliefs, set against the objective categories “asthma”, “medication” and “illness”, the approach developed from discursive psychology produced an alternative form of knowledge of the individual as constrained by and producing moral contexts of illness management and medicine taking. In discussing asthma management, people could be seen, not simply to be reporting how they have managed their asthma, or how they view their condition and asthma medications, but also to be managing issues of blame and accountability linked to their actions and reported attitudes. This was evidenced by the rhetorical devices that participants were seen to deploy and the competing versions that they could be seen to manage, both from within a medical perspective of asthma management and from lifeworld conceptualisations of what it means to be ill and to manage illness appropriately. These culturally-available conceptualisations (Willig, 1999) could be seen as moral discourses which allocated blame and accountability for the same behaviour and attitudes in different ways, potentially raising difficulties for speakers when competing discourses were activated simultaneously within talk. Talk about asthma, illness and medications could be seen as a manifestation of these competing concerns, thereby repositioning the individual from someone possessing sets of attitudes to someone at the intersection of different moral discourses which need to be negotiated to participate in everyday activities. This study, using asthma as a case example, has therefore provided an alternative means by which talk about medicine taking might be understood and studied, suggesting the use of methods that enable the researcher to engage more closely with the issues that might influence the everyday talk and decisions of people with chronic illness and in which moral issues are foregrounded.

This study has also built on other discursive psychological approaches that have already researched talk about health and illness. First, whilst several scholars associated with discursive psychology may recognise the role of institutional discourse in producing meaning within interactions, this study has attempted to trace this path from institutional discourse to interactional talk, to understand how moral talk of medicine taking might have come about. It did so by moving beyond the transcript of interactions to examine moral connections within other forms of text that circulate society and which might have structured individual talk. This therefore extended the use of discursive psychological tools to help bridge the gap between individual utterance and broader systemic discourses. By doing so, the author was able not only to provide insights about what happens within interactions about asthma management but also to provide a critique of asthma management policies that influence those interactions. Incorporating an analysis of ethnographic contextual features that might have influenced the production of talk about medicine taking enabled conditions of interactions to be pinpointed that appeared to play a key role in the production of participants' talk. These conditions were related to how the research interactions were framed by researcher and participant and were not identifiable by a linguistic analysis alone. Developing the methodology to study ethnographic contextual features went beyond a more typical application of discursive psychology focusing only on interactions. This development allowed some generalisations to be made about the production of talk about medicine taking, both for people with asthma and other chronic illnesses. This provided distinctive lessons in how we might study issues about medicine taking in the future and also how clinical practice might be improved. The first of these was that talk about medicine taking may now be viewed as a performance and the second was that individuals' talk may be viewed as a manifestation of moral issues that may influence everyday decisions about illness management and medicine taking.

The first key generalisation enabled in analysing this study's findings, was that talk about prophylactic medicine taking could be viewed as a performance rather than as an articulation of one's views or behaviour. Goffman's (1959) use of the term "performance", has suggested that talk about medicine taking can be viewed as a public display that is organised by a "loose coupling" (Goffman, 1983, p.11) between social structure and individual agency. Here, people with asthma have been shown to present themselves in ways that may enable their continued participation in everyday activities

that are important to them. Such findings are supported by earlier research which has evidenced peoples' need to construct their lives in ways which enable their participation in important everyday activities such as work (Charmaz, 1990; Frank, 1995; Yoshida, 1993). This view of the person with chronic illness implies that their talk about illness and treatment cannot be simply treated as an accurate articulation of how that person engages with their condition, nor as representing a specific attitude about their condition or medication. Instead, such talk can be seen as a continuously-constructed performance and it is these performances that may be interpreted, evaluated and categorised within interactions rather than an actual attitude or behaviour. This has the potential to lead to clinicians and researchers inappropriately categorising how people manage their own condition and prescribing treatments which may be inappropriate to how those individuals live with their condition in everyday life.

The structure provided within the research activities surrounding this study indicated that how performances are categorised is likely to differ according to the criteria used to allocate such categories. Within a clinical interaction which uses asthma guidelines to structure the care of patients, these criteria could be whether individuals are considered "non-adherent" whilst also classifying them as potentially having inadequate asthma control and quality of life. In lifeworld settings, individuals' talk may be categorised in very different ways but in both settings the criteria for evaluating talk is unlikely to be made immediately explicit within interactions.

However, realising that people may attend to multiple moral discourses in their talk adds complexity to our understanding of people's performances beyond the immediate interactional context. This is to extend Goffman's use of the term "performance". Rather than being bounded by the immediate interactional context, people's performances about illness management can be seen as transferring linguistic resources across contexts that are manifested in different interactions. The "meaning" of performances therefore may result from how and how far different criteria, set up within interactions about illness management and medicine taking, match the available resources deployed by individuals with chronic illness. Effective performances may therefore be related to individual's ability to access and deploy the appropriate resources. In the case of asthma management this meant participants displaying a range of different versions of themselves including: responsible, actively engaged managers of their condition; someone equipped with accurate knowledge of asthma and the



medications; compliant; in control; someone with a health problem that is not an illness (Cornwell, 1984); someone not dependent on medications; a hard worker; a wealthy benefactor.

Further to this, the analysis of deviant cases in this study suggested that if people are to achieve appropriate treatment outcomes from consultations, or enable their participation in lifeworld activities such as work, they not only need to be able to access the linguistic resources that enable those objectives to be met but that they must also appreciate which resources are most likely to meet the criteria that determines how they will be evaluated. Developing Goffman's concept of performance still further, evaluating talk about illness management may therefore be assumed to be subject to whether individuals have access to and display the required resources to meet specific interactional criteria. Positioning the individual as needing to align with clinical perspectives within consultations which review the management of their condition means that many people's linguistic resources regarding illness management, while functionally effective within their everyday lives may be considered inadequate when transferred to clinical or research settings. In the case of asthma management positioning oneself as having a health problem that is not an illness, responding to symptoms using a range of strategies including the use of a reliever inhaler may be functionally effective within a working context but classified as "non-adherent" and essentially irresponsible in a clinical consultation.

The second main generalisation from this study's findings concerned a theoretical relationship between talk and everyday decisions about illness management. Talk about illness management has been shown here to manifest different moral discourses that transfer across social historical contexts as well as being a product of the contextual conditions in which those interactions take place. This evidence indicated that some of these moral discourses are likely to circulate the lifeworld settings of individuals, such as work, school, home or social settings. These moral discourses may therefore play a key role in shaping the decisions that people make about how they manage their condition. If so, this suggests a need to develop innovative research methods which might enable a better understanding of the relationship between these social settings and illness management. This takes a view of the individual within a range of semiotic spaces where the meanings attached to illness and medicine taking are situated not only by linguistic but by non-textual forms of discourse. The discursive psychological and linguistic ethnographic methodology developed in this study has provided a foundation

from which to develop suitable approaches in which to examine the connection between morality and individual decisions about illness management in lifeworld settings.

The novel insights offered here about the nature of talk about illness management and medicine taking suggest ways in which healthcare could productively change how it engages with people with chronic illness. To support people in ways which might be more beneficial both to them and to clinical practice, we perhaps need to set aside criteria that may categorise individuals in inappropriate ways as “adherent” and “non-adherent”, while ignoring what the patient may or may not be able to contribute to the clinical encounter. Rather than creating an interactional dynamic in which it is the patient who has to be able to utilise a particular set of skills to be treated appropriately, it is perhaps the clinician who should be helped to learn which linguistic resources will elicit patient performances that can engage with the moral contexts of patients’ everyday lives.

However, clinical consultations are subject to specific institutional and interactional conditions, which will facilitate some moral talk whilst marginalising or excluding other, potentially important discourses. There is therefore a need to investigate how restructuring clinical interactions might be possible to help avoid excluding discourses that might be important in the decisions that people make about taking medications.

The findings reported in this study suggest that restructuring clinical consultations might include repositioning the discussion about a patient’s condition away from a focus on physical symptoms and towards a discussion of their everyday activities. The issue then becomes about whether there are any existing treatments that are compatible with patients’ everyday activities which might enable them to participate more effectively in those activities, rather than discussing specific symptoms and how to control them. This shift in the discussion therefore opens the possibility for grounding patients’ talk in the everyday moral issues that influence their decisions, and patients’ discussion of those treatments offered as indicative of their concerns set within those everyday moral discourses. Treatment decisions may therefore include non-adherence as a treatment option, recognising that this decision is set within a lifeworld context where other important social acts and identities are upheld by this decision. The role of the clinician and clinical advice is therefore not to develop more effective techniques to

persuade patients to take prophylactic medications but to recognise the limitations in prescribing a treatment that is incompatible with individual's daily lives.

Helping clinicians to engage with the interactional and moral dilemmas faced by people with chronic illness in talking about and managing their condition, may well create more opportunities for collaboration between doctor and patient and for offering a clinical decision-making process in which the voice of the patient can be genuinely heard.

## Appendices

The following appendices (A to D, plus published article and CD) have been included for different reasons. Appendix A and Appendix B.1. will help the reader understand how the research interviews were conducted and transcribed. Appendix B.2. and B.3. provide additional information to help the reader understand the author's decision-making in undertaking the analysis. Appendix C provides additional information that assists with understanding how participants were recruited but which also informs the author's interpretation of interview data described in Chapter Five. Items included in Appendix D demonstrate additional work that was undertaken in this PhD study, which although did not form a key part of the thesis text, either influenced the development of the study or complemented the main analysis undertaken in Chapters Four to Six. The copy of the published article (Murdoch, Poland, & Salter, 2010) has been attached as supporting information and the enclosed CD includes all full transcripts of interviews that have been cited in the main text, allowing the reader to follow-up these citations. The following list is a summary of items included in the appendices.

- Appendix A. Interview Topic Guides and Focus Group Protocol
  - A.1. Interview Guides and Topic Cards for Face-to-Face Interviews
  - A.2. Data-Sharing Focus Group: Protocol
  
- Appendix B. Analysis of Transcripts for Evidence of Rhetorical Devices and Moral Discourses
  - B.1. Transcription Conventions
  - B.2. Questions to ask when Analysing Transcripts
  - B.3. Transcript Excerpts
  
- Appendix C. Recruitment of patients into the ELEVATE Study
  - C.1. Extract from final report documenting recruitment procedure and selection criteria
  - C.2. ELEVATE Screening Questionnaires
  - C.3. Medication Adherence Report Scale (MARS) Questionnaire
  - C.4. Patient Information Sheet and Consent Form
  
- Appendix D. Other work undertaken not included in main text

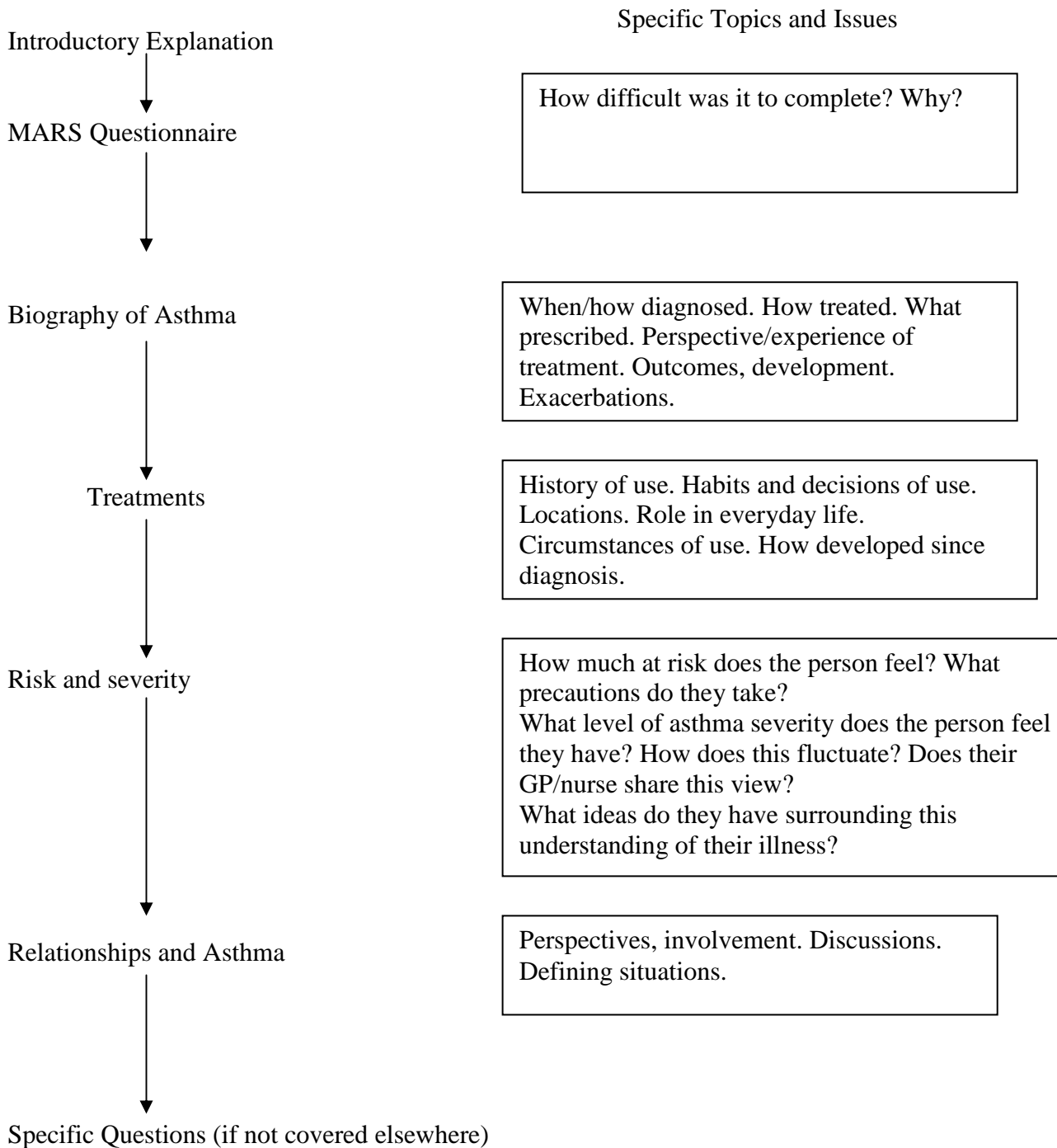
- D.1. Analytical Process to Identify Participant's Accounting Styles
- D.2. Ethical issues regarding informed consent with individual participants.
- D.3. Reflections on focus group and role of moderator
- D.4. Analytical work Undertaken on Rhetoric and Discursive Space
- D.5. Review of Health and Illness Literature to Assess the Relevance of Morality for talk about Health and Illness
- D.6. An Interpretation of the ELEVATE Recruitment Process and Participants Access to Discursive Resources

## Appendix A

### Interview Topic Guides and Focus Group Protocol

#### A.1. Interview Guides and Topic Cards for Face-to-Face Interviews

##### *Loose structure/format of first interviews*



### *Topic cards*

#### Biography of Asthma Card (1<sup>st</sup> Interviews):

- When/How diagnosed. How treated. What prescribed. Perspective/Experience of treatment. Outcomes, development. Exacerbations.
- When/How diagnosed with asthma? Why did you go to doctors? What happened? How was it decided it was asthma? What explanations were provided? How did you feel about diagnosis?
- What was prescribed? What explanations were provided? What did you think about the treatment? Were alternative types offered or just one? Was a review visit arranged?
- How did you get on? What did you think about taking treatments as prescribed? What did your relatives think? What changed after diagnosis and prescription? Did you attend a review visit? Why? Why not?
- Has anything significant happened since then? How felt? Dealt with? What changed afterwards?
- (If 2<sup>nd</sup> interview) What has happened since last interview?

#### Treatments Card (1<sup>st</sup> Interviews):

- History of use. Habits and decisions of use. Locations & circumstances of use. How developed since diagnosis. Role in everyday life.
- How do use your treatments? When? Where? How did you arrive at that decision? Has it always been like that?
- How often do you not take your preventer? How do you feel about that?
- Remember things which have stopped you from renewing prescription?
- How long do they think treatment takes to have full effect?
- Where do they expect the treatment to work?
- Do they see any limitations with inhaled steroids (ICS)? Do they feel that ICS reach all parts of their lungs?
- What goals do they hope to achieve as being part of the study? Perhaps refer to their patient-centred targets?
- Do you carry your treatments with you at all times? Do you notice/think about your asthma every day? Have you ever forgotten your inhalers? What happened?

- Have there been any situations when you felt you needed your inhaler but did not want to use it?
- Have there been any situations where your asthma has been very noticeable?
- How do you see the future in terms of asthma and medication use?

#### Risk and Severity Card (1<sup>st</sup> Interviews):

- What ideas do they have surrounding this understanding of their illness? Try to ground in experience.
- How much at risk does the person feel? What precautions do they take?
- What level of asthma severity does the person feel they have?
- How does this fluctuate? How would they define their condition? Is it something they feel is with them everyday? Does it need to be managed everyday?
- How random are their asthma episodes? How easily can they predict it getting worse? Is that easy to live with? What would be easier?
- What does this mean for medication use? How bad would it have to be to make you take your medication everyday?
- How does this compare to other people with asthma? Does their GP/nurse share this view?
- LINK —————> Habits with inhalers.
- What causes the person's asthma to get worse? Examples
- What happens when you go to see the doctor or nurse about your asthma?
- Do you discuss everything you would like to?
- Do you discuss asthma along with other reasons for going, or on its own?
- Do you think about the long-term and your asthma?
- Other people with asthma? LINK—————> Causes of illness in general. Role of medications in the prevention of illness.

#### Relationships and Asthma Card (1<sup>st</sup> Interviews):

- Perspectives, involvement. Discussions. Defining situations.
- Do you discuss your asthma with anyone apart from your GP and nurse?
- What role do relatives play?
- Do you know anyone else with asthma?
- Have there been any situations where your asthma has been very noticeable?
- Would you like anything to be done differently in the way your asthma is treated?



- Specific Questions (if not covered elsewhere)

### *Loose structure/format of second Interviews*

The following is the guide that was used when conducting second interviews. In contrast to the first interviews, the topics listed here were not asked in any particular order. In addition, participants were re-consented (see Appendix D for rationale) following the development of the study beyond a specific focus on medications.

- Re-consent participants: Say “I would like to understand not only your views about asthma and medication, but more specifically the reasons why you have these views”. Explain that understanding this may involve discussing how the person views health and illness in general, lifestyle choices and the person’s attitudes to life in general. Remind participants about anonymity/confidentiality and offer opportunity to withdraw.
- Remind participants that the interviews are part of a student project and are in addition to the main study. Do not have medical training, not here as an advisor.
- Biography Since Last Interview:
  - Use of preventive medication- what has happened since last interview? Why? (What are the relative differences between the 2 medications?)
- Risk:
  - Can you tell me about unsafe/risky situations in your life since you’ve been living here?
  - Can you tell me about a time when your health/asthma has been at risk?
  - Can you tell me what happened?
  - Can you tell me about a time when you felt that you were overcoming your breathing difficulties?
  - Can you tell me about a time when your asthma affected you badly?
  - Can you tell me what happened?
  - Tell me about a time you were in fear of your health/asthma?
- Medications:
  - Can you tell me about a time when you relied on having your asthma medication with you?
  - What about now?

- Can you tell me about a time when you were unhappy with your medication/inhalers/tablets?
- What about now?
- Life Goals:
  - What sort of person would you say you are? How would you describe yourself? How does health (*then specifically asthma*) fit into this?
  - What do you like to get out of life? Do you have any specific goals?
  - Can you tell me about a time when you have had problems pursuing these goals?
  - What about now?
  - Where does health (*then specifically asthma*) fit in to this perspective?
  - Are these goals affected by your health?
  - Asthma goals – what are they?
  - When you are looking after your asthma what are your main aims? Anything else?
  - Can you tell me about a time when these goals were not met?
  - What about now?
  - Would you say your lifestyle or anything about yourself has changed since the last interview? What are the differences between before and after entering the study?
- Health and Illness
  - What are the aspects/characteristics of a healthy person?
  - What are the aspects/characteristics of an ill person?
  - What would you describe as an illness?
  - Can you tell me about a time when you would see yourself as an ill person?
  - Can you tell me what happened?
  - What about now?
- Doctor-patient relationships
  - Can you tell me about a time when you were happy with your doctor or nurse.
  - Can you tell me about a time when you were unhappy with your doctor or nurse.
  - Why don't you take your medication? Do you still pick it up? Does the GP think you should take it?

- Can you tell me what stops you from taking your GPs advice?
- Do you feel that is your decision to make?
- Is it important to you to feel you are making the decisions about your med taking?
- Do you see any consequences for your choices?
- Do you think there is any long-term risk in non-adherence?
- Future:
  - Have you thought about your health/asthma in the future?

## **A.2. Data-Sharing Focus Group: Protocol**

Location: Centre for Adult and Continuing Education, Norfolk

Participants: No more than 10 people, at least one person from each accounting style.

Seating/Materials: Round a table. JM to sit just back from the table to try and emphasise the discussion involves them not me. Paper and pen for each participant. Copies of vignettes. Table Mics and tape recorder.

Thank everyone for attending. Introduce myself, remind them that everyone here all participated in the asthma study and were also interviewed by myself for my student project.

### ***What will happen in the focus group***

“What we will be doing in today’s group will be to have a good discussion and to get your reactions as a group of people who may well have some differing views, to some of the findings from the first interviews. The materials I will be showing you are sets of opinions that different people may make. They have no names attached and are not taken from any one interview. They have been put together, from my own interpretations after I closely examined the different ways that people in interviews talked about their asthma.”

- i) This is a chance to talk about what **you** think.
- ii) I’m recording the discussion and I plan to transcribe what you say, but your names will not be used in the resulting transcription.
- iii) Later on in the research I will want to quote some of your words because sometimes using real people’s words can often be the best way to show what issues matter. But this won’t be done in a way that would allow anyone to be identifiable.

### ***Ground rules***

To help ensure everyone is comfortable with the discussion I would like to ask everyone to agree these ground rules:

- i) No one to discuss the details of what is said afterwards, or outside this room
- ii) Respect everyone else's contribution – even if you disagree with it
- iii) No using insulting language to each other

Is everyone happy to agree these?

I hope we will have an enjoyable and interesting time.

Tell the group I will make a few notes. These will be about who is speaking when so when I listen to the tape I can understand who I am listening to. Pass round the numbers and explain that I will just note down the number and a brief note about what is being talked about.

### ***Ice breaker: From (Crossley, 2002) 5-10mins.***

Tell participants that before the main group discussion, I'd like them to think of two people they know, one 'healthy', the other 'unhealthy'. Divide piece of paper into 2, left side write down 3 characteristics of a healthy person, on the right 3 characteristics of an unhealthy person. Then feedback what they have written to the person sat next to them. When finished ask them to briefly tell the group a couple of things that they talked about.

This is to help prepare participants to discuss the vignettes between themselves rather than to and from me as moderator and also primes them for the reflexive task of comparing themselves with each vignette.

### ***Anonymous Vignettes ("findings from interviews") of 4 out of 5 accounting Styles***

Each vignette is a representation of 'attitudes' that can be seen in the data from Phase One interviews and what I consider to make up each accounting style. Whilst I have created each sentence within the vignettes, some of the words and phrases are direct quotes. Each vignette is spoken in the 1<sup>st</sup> person to elicit responses from focus group participants that position the speaker in relation to the person they consider to be represented in the vignette. Relational positioning is a key rhetorical strategy in

accounting for one's own health (Radley & Billig, 1996), and is evident throughout Phase One interviews.

Tell the group that I am going to pass round some of the findings from the one to one interviews and I'd like them to discuss them as a group. Pass the first vignette round, a copy for each participant. Remind them that the person speaking isn't a real, individual person. What they show is how several people I interviewed talked about their asthma.

Read the text aloud and ask them "What do you think of this person's opinion?" Wait 15-20secs. If nobody speaks then focus in on part of the vignette (e.g. *Medications are necessary to control my asthma but I don't rely on them.*) and ask again "What do you think about this?" Keep representing if necessary. **DO NOT OFFER ANY OF MY OWN IDEAS ABOUT THE VIGNETTE.**

**Text in bold italics was the text (vignette) that was presented to the group. The preceding plain text is the description of the accounting style.**

1. *Compliance as passive:* The participant positioned her(him)self as engaged with their asthma, emphasising themselves as responsible and in control. There was a frequent use of the self-regulatory repertoire to position her(him)self against those who uncritically comply with medication instructions. This was an active rejection of compliance as an ideal.

*Medications are necessary to control my asthma but I don't rely on them. I decide for myself whether I need to take a particular medication. Some people use medication for the sake of it and are dependent on it. I assess how I feel and then take the necessary action.*

2. *Minimisation repertoire using several rhetorical devices to justify medicine taking.* Participants with this accounting style either claimed that they did not have asthma, or that their condition was too mild to warrant adherence to prophylactic medication. Their own version of their condition was pivotal in justifying non-adherence to prophylactic medications, but did not blame healthcare for any mis-diagnosis.

***I do not have proper asthma. I have very few breathing problems and the brown inhaler doesn't make any difference to the way I feel. I don't have any concerns about taking medication but I often forget to do so.***

3. *Tension between lifeworld and medicine. Adherence potential threat to lifeworld:* Participants positioned prophylactic medicine taking as incompatible with activities in their everyday life. However, individuals with this style appeared to resist challenging the medical directive on adherence.

***Asthma is a nuisance, an inconvenience but it doesn't interfere with my life. I use my blue inhaler to stay in control of my asthma and I avoid situations that affect my breathing. I should take the brown inhaler everyday and it is my fault that I haven't, but I don't want to be hooked on too many medications.***

4. *Blame of healthcare breaches sick role contract:* Participants blamed healthcare for not identifying the “real” cause of symptoms or for not communicating with them effectively regarding their condition and health generally. Taking prophylactic medications was therefore positioned as potentially treating the wrong condition.

***I don't think I have asthma. I think doctors and nurses do not understand my symptoms and I don't feel that they listen when I go to see them or talk about the causes of asthma properly. I am concerned about the side-effects of medications. The experts say that some medications are now unsafe so I don't want to take a medication everyday that I don't think works very well.***

### ***Management of discussion***

- Latecomers: Expecting 10 people maximum so will start either when 8 are present or after 15mins.
- Methodological confusion: Potential danger that participants spend too much time figuring out what to do and not actually discussing the statements. The icebreaker and representing the vignette is the strategy to deal with this. On this point it is essential I do not offer my own opinions as this type of intervention

undermines the whole point of having the focus group – which was to provide a different piece of data that isn't subject to the same kind of interactional conditions as the face to face interviews, where I potentially represented an NHS, medical figure to which they were responding to.

- People dominating or too many people speaking – will need to judge whether and when to interrupt. If I do interrupt look around the other participants and ask “What do other people think?” Do not target any one particular person.



## Appendix B

### Transcription Conventions, Analytical Questions and Transcript Excerpts

#### B.1. Transcription Conventions

The following conventions were based on the system developed by Gail Jefferson in Atkinson and Drew's "Courtroom Metaphor" (1979).

[ ]	Square brackets mark the start and end of overlapping speech. Position them in alignment where the overlap occurs.
Underlining	Signals vocal emphasis; the extent of underlining within individual words locates emphasis, but also indicates how heavy it is.
↓    ↑	Vertical arrows precede marked pitch or intonation movement.
CAPITALS	mark speech that is obviously louder than surrounding speech (often occurs when speakers are hearably competing for the floor, raised volume rather than doing contrastive emphasis).
°I know it,°	'Degree' signs enclose obviously quieter speech (i.e., hearably produced-as quieter, not just someone distant).
(2)	Numbers in round brackets measure pauses in seconds. Place on new line if not assigned to a speaker.
(.)	A micropause, hearable but too short to measure.
solid.= =We had	'Equals' signs mark the immediate 'latching' of successive talk, whether of one or more speakers, with no interval.
hhh	Aspiration (out-breaths); the more hh the longer the out-breath.
.hhh	Inspiration (in-breaths); as for out-breaths.
y'know?	Question marks signal stronger, 'questioning' intonation, irrespective of grammar.
((text))	Additional comments from the transcriber, e.g. context or intonation.
(??) or (text?)	Inaudible speech on tape. A guess as to what was said may be inserted with a question mark.
heh heh	Voiced laughter.
sto(h)p i(h)t	Laughter within speech is signalled by h's in round brackets.

she wa::nted	Colons show degrees of elongation of the prior sound; the more colons, the more elongation.
>he said<	'Greater than' and 'lesser than' signs enclose speeded-up talk. Sometimes used the other way round for slower talk

## **B.2. Questions to ask when Analysing Transcripts**

The following questions were used in applying discursive psychological tools to identify evidence of participants justifying their asthma management.

What context was the version of events/asthma etc being set within? What is the purpose of what is being said? What version of themselves are they constructing? What alternative versions are being discredited? How are they doing this? What/Who do they blame for this behaviour? What "facts" are prevalent in the text? How were "facts" used? How were metaphors and stories used? What emotive vocabulary was used? What references were used to add authority to the account? How were timeframes used? What were the participant role patterns, (e.g. self as moral agent, doctor as "professional"). How were pronouns used and linked to verbs. What categories were constructed by the speaker? How were objects such as asthma, health, illness, medications constructed? When was the active or passive voice used, and what choice of expressions were there (e.g. good patient, compliant).

Were similar positions were being constructed in other sections of the interview? Are there any important similarities or differences in what and how the text is being built? How do sections not explicitly discussing asthma management inform the analysis?

### ***Interpretative repertoires***

What kinds of interpretative repertoires did the interviewee deploy during the interview? What evidence is there to support that interpretation?

Was only one repertoire used when discussing a particular topic? At what sorts of points are different repertoires used? This step also involves looking for whether different repertoires create new problems for the speaker? Is there a particular combination of repertoires as Wetherell suggested (M. Wetherell, personal communication, February 2,

2006) that creates “trouble” for the participant? Are there any tensions between repertoires? Do the participants orientate to these tensions? How do they manage these difficulties? A note of caution is needed here about contradictions that can be seen in a participant’s talk. What may appear as a contradiction may have some supportive causal link which made sense in the context of the interview. The issue for any discursive tension is whether the sequences of talk are closely linked in the interview. Has the person shown some management of this contradiction? If not then the analyst might hypothesise about a circumstance when this contradiction might be salient but needs to acknowledge if the participant’s orientation is absent.

What evidence is there in the rest of the interview which creates a problem for the interpretations developed?

### ***Blame and accountability***

What versions of themselves and their behaviour were being constructed through the different devices and repertoires within the interaction? Was there evidence that the interviewee was managing a potential threat to this interpretation? Was there evidence that alternative versions were being discredited by the interviewee? How did the interviewee want to be understood?

### ***Moral discourses***

How might these different versions be interpreted from different perspectives both in medicine and in participant’s lifeworlds? What links were there to the moral discourses discussed in Chapter Two around appropriate illness management as seen from the asthma guidelines? Was there evidence that older discourses of asthma and emotional control were being deployed? Could interviewees be seen to utilising contemporary notions of illness prevention or those relating to symptom control as seen in the latter half of the 20<sup>th</sup> century? What other discourses were being activated outside of medicine and does the participant’s talk contribute something new to these different discourses?

### B.3. Transcript Excerpts

The table below summarises the excerpts from interview and focus group data that have been included in Appendix B.3. Each excerpt includes one of the extracts that were reported in the analysis chapters. The excerpts enable the author's choice of extracts to be examined and facilitate further insight of how participant's versions were sequentially constructed within the interactions taking place.

<b>Excerpt Number</b>	<b>Participant number</b>	<b>Pseudonym</b>	<b>Excerpt details</b>	<b>Extract included in main text</b>
1	500367	Dave (D)	Interview 2, pages 3-7, D's home	Extract 1, Chapter 4
2	121221	Irene (I)	Interview 2, pages 1-4, I's home	Extract 2, Chapter 4
3	660345	Stephen (S)	Interview 1, pages 17-20, S's home	Extract 6, Chapter 4
4	670287	Martin (M)	Interview 1, pages 10-13, M's home	Extract 9, Chapter 4
5	670289	Dawn (D)	Interview 1, pages 17-20, D's home	Extract 10, Chapter 5
6	650405	Janet (J)	Interview 1, pages 7-11, J's local GP surgery	Extract 12, Chapter 5
7	261284	Frank (F)	Interview 1, page 7, line 1 to page 8, line 29, F's home	Extract 14, Chapter 6
8	Focus group	Participants numbered 1 to 6	Page 26-29, adult education centre	Extract 16, Chapter 6

**Table 1: List of Transcript Excerpts included in Appendix B**

1  
2 D: I've probably still got one kicking around  
3 somewhere.  
4  
5 JM: So can you just talk through, since I last saw you  
6 about a year ago what's happened in terms of your  
7 medication use? What?  
8  
9 D: Well at, at the moment, what I do now is tablet  
10 twice a day (1), but I've got (1) one thing that has  
11 changed (1) the (name) practice had a policy (3),  
12 more financial than any other reason (1) of taking  
13 people off ventolin and putting them on to  
14 becotide.  
15  
16 JM: Right.  
17  
18 D: (??) Then they tried something else which was  
19 even cheaper (1) becotide and the other one (2)  
20 didn't work (1) they just didn't. Well they, they  
21 didn't work would be not quite right (1), they  
22 didn't work as effectively as ventolin does.  
23 Ventolin worked beautifully (1) cleared it there  
24 and then (1) and I (3) had my repeat prescription  
25 dose halved right. (1) They were insistent that I  
26 have the brown inhaler and (.) the blue one (2). Ok,  
27 I was having two or the blue ones at a time (1), no  
28 you can't do it you've got to have one. (??) ok.  
29 Then I got on to this asthma (1) study (1) and (1)  
30 (Name) very kindly changed it back so that I could  
31 have a ventolin as opposed to one of the others (1),  
32 quite a while ago now and that's been (.)  
33 wonderful (2). It really has. (1) It's made world of  
34 difference.  
35  
36 JM: So that's you, you've still got your ventolin?  
37  
38 D: Yeah.  
39  
40 JM: Yeah.  
41  
42 D: (2) I'd get through a ventolin probably (1) about  
43 one (2) a month, five weeks, four – five weeks (2).  
44 Something that (??).  
45  
46 JM: (2) ok, a, and that's, how long has that been (.) the  
47 situation?  
48  
49 D: Oh, years. (1) what that I've used ventolin?  
50  
51 JM: Well you, no, you sort of saying you'll use it once  
52 every four or five weeks or?

1  
2 D: No, no, no I don't use it once every four weeks, I  
3 have a new one every four or five weeks.  
4  
5 JM: Sorry, right.  
6  
7 D: I use (2) I'd say quite, you know probably I would  
8 only, you'll have a day like today when the  
9 weather suddenly changes (.) and I will probably  
10 use it at some point during the proceedings of  
11 today (1) and probably again at night time if it.  
12  
13 JM: (1) Yeah.  
14  
15 D: It's impossible to judge. (.) And you'll have a day  
16 (1) when the sun shines when you, you just don't  
17 (.) at all. (3) It's a different thi, I mean (2). I've  
18 heard the argument about air quality and (.)  
19 everything else but I mean (3), this isn't a city full  
20 of smog I mean it's (2) I work on the edge of quite  
21 a big city but,  
22  
23 JM: Yeah.  
24  
25 D: The air quality isn't perfect but it's all we've got  
26 (3) down here in the swamp part of ((place name))  
27 we have to put up with what we can I'm afraid it's  
28 (2). Yeah I'm sure, I'm sure it certainly, I've been  
29 on (1) we've got friends that live up in the lake  
30 district (1) and I've been up there (1) for (2) a  
31 week and certainly two or three days into that it's  
32 amazing the difference. I can breathe a lot, lot  
33 easier than down here.  
34  
35 JM: Down here?  
36  
37 D: Yeah.  
38  
39 JM: Even though you live in the country?  
40  
41 D: Even though I live in the country, yeah, yeah.  
42 Living in the countryside and then they grow a lot  
43 of, my family are farmers so I mean, I'm the worst  
44 person in the world (1), but they grow a lot of oil  
45 seed rape around here, an awful lot of weed.  
46  
47 JM: Right, right, right.  
48  
49 D: (2) Yeah.  
50

1 JM: (1) So what, what are the differences do you think,  
2 or the relative difference between (1) eh, tablets  
3 and the brown inhaler?  
4

5 D: (3) I think it's, I think there's an element of  
6 psychology comes into it. (1) And I think there's a  
7 degree of psychology comes into everything (1) in  
8 as much as (.) partly because I think those tablets  
9 are doing some good (.) it's certainly got to help  
10 the job a lot (1) help the fact that they are.  
11

12 JM: Yeah.  
13

14 D: (2) Em, (1) the brown one I'm absolutely, I've  
15 managed to convince myself beyond a reasonable  
16 doubt, it doesn't work or its effects are (.)  
17 minimum, minimum effectiveness. (2) I know, I,  
18 I've had (1) asthma (1) all my life. I've you know,  
19 I started with the little pink tablet but through to  
20 the ventolin, then went on to the big white ones  
21 which were foul, before that we had spin halers  
22 and all these thing we used to have to put out  
23 fucking cups in and things and cracking and things.  
24 I've been through the full nine yards with this. (1)  
25 As soon as ventolin appeared (1) instantly you  
26 have something which is a cure (1) (??). You went  
27 from having (1) asthma (1) to using it (.) to being  
28 perfectly normal again (1), like that. (1) It was (2)  
29 a big, big difference. (5) The brown, I mean with,  
30 I've had two or three or four different doses of the  
31 brown one and I've played about with it for (1) a  
32 week, for (.) nine months sort of thing, and I'm  
33 adamant that it's not made any difference. (3) It  
34 really hasn't. (1) Yeah and I did forget to take it  
35 and I did forget to, it was just (.) h, how (4) and  
36 the, this thing about using the two in conjunction.  
37 (1) Well, (2) it just, I just never (1) really accepted  
38 it.  
39

40 JM: (1) So is it, is it just the eh (3) the drug itself or is it  
41 the device that, that's in it as well [is there  
42 anything else about]  
43

44 D: [Oh no, I don't think] there's anything (??). No.  
45

46 JM: It's not like I  
47

48 D: (3) I, (2) it's, it's, I, I have experimented with it  
49 and, and you know a week playing with it and then  
50 a week without it and then a week with it and I  
51 really can't tell you that there, that there was a  
52 great deal of difference among any.

1  
2 JM: Right  
3  
4 D: There really was none (?) (2). I've been better with  
5 these tablets in as much as I know for a fact that I  
6 have ordered less ventolin (.) since I've been using  
7 those than I was before.  
8  
9 JM: (1) Do you think you've eh, (1) taken (.) the tablet  
10 more regularly?  
11  
12 D: I've taken the tablet, yeah.  
13  
14 JM: Right.  
15  
16 D: Oh definitely, definitely (2).  
17  
18 JM: What would you say about the (2) given what  
19 you've said about psychology (2) what you know  
20 about it and the fact that you definitely taken them  
21 (??) more regularly (1) what do you think the  
22 possible differences in treatments?  
23  
24 D: (3) Well I mean there's lots, for all I know they  
25 could be the same thing, two different formats, (.) I  
26 don't know I mean I'm not (3). Going back to what  
27 I said at the beginning (1) I think there's an  
28 element of psychology in as much as (.) because  
29 I'm (1) pretty adamant I've been told that this will  
30 (1) help effectively but, (.) I've been taking it, I've  
31 been going along with it, I've certainly as I said,  
32 used less ventolin at the same time (2). No, no  
33 problem at all. (1) Brown one was very hit and  
34 miss in as much as I would forget to take it didn't  
35 matter where I put the thing. (2) I had them  
36 scattered, I had one in the car, one in the, beside  
37 my bed, one in my office and I'd still forget to take  
38 it. (1) I don't know why but I just did.  
39  
40 JM: (3) That's interesting.  
41  
42 D: (2) I think it was, I think it was (1) the fact that (1)  
43 it, it's so similar to the original (.) the blue one, the  
44 ventolin (.). That (1) you use when you've got  
45 asthma, when you're having an asthma attack or  
46 (??), you use the (??) (1) and it's (1) that's a cure,  
47 you pick it up, you reach for it at that point (2) to  
48 (1) go to the action of using exactly the same sort  
49 of (1) when there's nothing wrong with you, is not  
50 a natural (2), and I think there is an element of that  
51 feeling.  
52



1 JM: Yeah, that's interesting. (3) I was just going to pick  
2 up on a point you made last time I was here, (1)  
3 which was (1) the, the, that there was cure (1) for  
4 your form of asthma ie. Ventolin  
5

6 D: Mmmm.  
7

8 JM: And eh, (1) preventative medication was then  
9 something which came in recently [or relatively  
10 recently]  
11

12 D: [well that, that is] it is relatively recently (1) and  
13 (2) up until (2), it's only up until those tablets it (.)  
14 had (.) far to go. (3) preventative. I mean I (2), I've  
15 got two or three friends that have got the same sort  
16 of asthma as myself (1) and we're all pretty much  
17 on a par (.) in as much as our beliefs are (2) about  
18 what I just said.  
19

20 JM: Right. (3) d, do they, do they use (1) eh, any other  
21 medications?  
22

23 D: well they're still, they've not got the tablets.  
24

25 JM: No.  
26

27 D: they're not on the study but they are still using (.)  
28 the brown one in a spasmodic sort of way.  
29

30 JM: (1) Right. (2) And have you, do you think there are  
31 differences in your (2), your, your ability to sort of  
32 so things? Do you know what I mean, like (3) what  
33 you were doing before?  
34

35 D: (5) I certainly think that the (1), the, the things that  
36 usually trigger (1) asthma are (2) not necessarily  
37 always the things you forget (??) (1) If you'd  
38 expect something, if I left here and forgot to take  
39 (2) my ventolin with me (2) I could pretty much  
40 guarantee that I would suffer asthma at some point  
41 during the proceedings (2) before. (1) Now, that is  
42 certainly less likely (6). You know, before you of  
43 thought oh my god I haven't got and then it's  
44 inevitable you're going to have an attack. Now it's  
45 more case of oh, it well it doesn't matter I've got a  
46 tablet (??).  
47

48 JM: Right, (4) do you think you're an advantage to (2)  
49 your friends (1) like (??)

- 1  
2  
3  
4 JM: Ok, I just wondered if you can tell me, (1) I, I was  
5 here about a year ago wasn't I? Em, and you had  
6 just entered the study then (.) and you were  
7 prescribed (1) eh, a tablet I think.  
8  
9 I: That's right I've got to confess I don't (1) very  
10 much take it now but em, (1) I take so much  
11 medication at the moment, (1) you know and I  
12 didn't think (.) that that made that amount of  
13 difference to me. (1) I just stopped, you know?  
14  
15 JM: How long after (1) you were prescribed it?  
16  
17 I: Oh, about I only stopped about couple, two or  
18 three months ago now. (1) But at the time, (.) I  
19 thought I'd finished the study anyway and I just.  
20  
21 JM: Mmmmm.  
22  
23 I: °I got to admit I just found other ways (??) °.  
24  
25 JM: What ways?  
26  
27 I: Well, if that's in your way just throw them there.  
28 I'm eh, (1) just back to my normal medication and  
29 (1) I still have to take that every night. (1) I suffer  
30 cramp a lot, I take a cramp tablet, I take pain  
31 killing tablets at night, (1) and I just think that's  
32 keep pushing tablets into me (.) I ain't really,  
33 really into that much, (1) you know? (2) °So I just  
34 didn't (.) bother too much°. (1) You see the thing  
35 with the asthma thing is (1), that ain't my  
36 primarial, (1) I, I have asthma, I have asthma  
37 attacks (1) especially my worst times are (1) as I  
38 told you before, (.) when the windows have to be  
39 closed due to inclement weather outside (1) and  
40 that then I can guarantee I shall have an asthma  
41 attack in the night (.) but, (.) it's either that or (.)  
42 get blown out your bed almost, you know cos our  
43 windows aren't designed (2) so that, you know  
44 that's a stupid window we got up there, (1) and  
45 that blow right through and em, (1) he's got  
46 tinnitus in the ear and he got ear ache once through  
47 it. (1) So I have to just close it down (1) but  
48 otherwise when I got it open and get (.) (??)  
49 indoors (1), I generally you know don't, (1) I  
50 won't say I suffer as much perhaps some others.  
51 When I do get it it frightens me (1), you know? I'm  
52 always taking my (1) eh, puffer with me

1 everywhere (1) but just before Christmas (2), I had  
2 a em, (1) I had the flu injection in October (1), now  
3 I don't know whether that was relevant or not cos I  
4 have the flu injection every year, (.) but this  
5 particular year, (.) last year (1), I had very bad bout  
6 of bronchitis (1) and I was on antibiotics (2) and  
7 (1) that didn't clear it up and I had to have another  
8 dose of antibiotics. That really went on for about  
9 (3) all of two months that did you know (1).  
10 Concurrent and I just couldn't breath (.) and course  
11 I mean I had to use the puffer (.) more frequent  
12 than ever (.) for that (1) and that was really nasty.  
13 (1) But as I said I have occasional bouts what, but  
14 mostly if the weather (1) and I can get some air (1).  
15 I do get it (??) as well but not so much you know?  
16 (1) So I don't, I've got so many other things it's  
17 like, you, you know so, but I just, that ain't a  
18 primarial problem. That is when I get it (1) cos I'm  
19 afraid I'm gonna die cos I hate, (1) I think it would  
20 be an awful death. (1) gasping, (1) but (1) the other  
21 things I got are like arthritis is fine and the pain (1)  
22 dominates my life. (2) And the condition I now  
23 told you about that's eh, (1) I've had a major  
24 operation for (1) em, (2) adhesions and for some  
25 reason or other, I don't know why (1) I just, you  
26 know, don't really like (1) now, say if I was talking  
27 to you, I'd have to go now but I (??). (1) That's,  
28 that wrecked my life. (1) Where ever I go (1),  
29 when that come on (1) I have to go (1) and that's  
30 not pleasant. (1) As a child you know, there can be  
31 holiday's that, days out (1) I take Imodium for that,  
32 (1) if I do and sometimes that don't even work. (1)  
33 So what, what with that and (1), and the pain of my  
34 asthma, em , my arthritis (.) you know, that's all  
35 just (1) combination of things, (1) and my general  
36 (1) eh, (.) feelings on illness itself is em, (1) I think  
37 that's the price we pay with God, (1) it seem like to  
38 me (1) because em, (2) these things just sort of  
39 seem to happen (1) in an almost way you know?  
40  
41 JM: mmmm.  
42  
43 I: (1) And also I think that (1) the arthritis is ruled by  
44 the weather. (1) Now today it's nice and dry (1)  
45 and I shall be alright today. (1) I can tell you when  
46 it's wet without even looking (1) cos the pain is  
47 horrendous (1) it's like having toothache in your  
48 back and all down your neck.  
49  
50 JM: mmmm.  
51

1 I: And I just em, (2) as I say I've got so much going  
2 on (1) in my actual (3), on the whole (1) one  
3 doesn't, you know unless it happening (2) I don't  
4 think too much about these things (1) you know,  
5 (1) unless they're actually occurring do get?  
6  
7 JM: Yeah.  
8  
9 I: Do you understand that?  
10  
11 JM: yeah, so you, when you entered the study and you  
12 were prescribed the tablet.  
13  
14 I: Mmmm.  
15  
16 JM: You said you stopped taking it two or three months  
17 ago, were you taking it every day or?  
18  
19 I: I took it every night. I had it up beside my bed, but  
20 what actually happened I lapsed (1) eh, over  
21 Christmas time (.) I didn't get one in because I  
22 didn't order it in time (1) and then I went without  
23 and then I just sort of (1) left it you know?  
24  
25 JM: (2) You said you didn't notice any difference?  
26  
27 I: I haven't noticed any difference because (1) I still  
28 had the attacks (1) you know, (1) but em, (2) as I  
29 said I've also got another one I take for (2) eh,  
30 (??). (2) Arthritis (1) now I don't like that tablet at  
31 all (1) I, and I don't even think that works either  
32 (1) [and actually  
33  
34 JM: What don't] you like about them?  
35  
36 I: Pardon?  
37  
38 JM: What don't you like about the tablets?  
39  
40 I: (1) I think you keep filling your body up with all  
41 these tablets and (1) you know (3), I don't know I  
42 just feel that, is that causing my problem (2), you  
43 see with my problem (1) my stomach problem (1) I  
44 just, I (??) with my stomach. (2) em, (1) I feel  
45 everything I eat (1) I get pain in here I ain't been to  
46 the doctors with it yet (1). Sort of there like, I don't  
47 know if I got an ulcer or what (.) and I, I think  
48 tablets (2) you know, (1) I don't know it might be  
49 me, I ain't really a (1) big fan of tablets. (1) You  
50 see but I have been taking them for years (1)  
51 coproximol and I'm saying years, no there're now  
52 telling you (1) that they're bad. (1) They going to

1 take them off the shelf, don't know if you saw the  
2 article?  
3  
4 JM: (1) No, I, I didn't see it, Em , (2) so (2) you didn't  
5 notice any difference with the [tablet at all?  
6  
7 I: Not really no] cos I still had the [asthma  
8  
9 JM: But you] (1) were happy just to carry on taking  
10 them?  
11  
12 I: I well, I, I mean I take things but as I said I just  
13 lapsed once (1) because they, I didn't order them  
14 (1) and you have to order them so many days prior  
15 (1) and that was all over Christmas (1) and I didn't  
16 feel any different so I just didn't (.) re-ordering.  
17  
18 JM: So are you using any eh, (1) are you using [the  
19 brown inhaler?]  
20  
21 I: [I, I have my] inhaler.  
22  
23 JM: (1) What, what a blue one?  
24  
25 I: Blue one all the time.  
26  
27 I: Is that all you have at the moment?  
28  
29 I: It is.  
30  
31 JM: How long have you (??) using that for? (1) Since  
32 Christmas has it just been the blue inhaler, you  
33 stopped taking the tablet?  
34  
35 I: Oh yeah the blue inhaler if I need it yeah. (1) I take  
36 it when I need (1) see that's my problem (1) if I  
37 need something (.) I grasp to it like that inhaler you  
38 see, when I'm having an (1) attack (.) that inhaler  
39 is in my hand and (1) inhaling it obviously (1) but,  
40 when I'm (1) going about my life (2) I don't eh,  
41 tend to (1) think. (1) It's like mostly on my brain  
42 (2) rightly or wrongly, you know I mean if I was to  
43 suffer with a real episode, obviously (1) I don't  
44 really think I'm (2)  
45  
46 JM: Have you [any  
47  
48 I: There] must be a lot of people, a lot worse than I  
49 am, honest.  
50  
51 JM: Have you had any attacks since?  
52

*Excerpt 3: 660345, Interview 1, pages 17-20, S's home*

1 S: ventolin and then maybe five, ten minutes later  
2 take (1) the, the Becotide, (1) or Beclomethasone  
3 or  
4  
5 JM: Yeah.  
6  
7 S: whatever.  
8  
9 JM: Yeah.  
10  
11 S: Em,  
12  
13 JM: (2) but (.) did you, how long did you take the  
14 brown, the brown one for the first time or anytime  
15 you've taken it how long did you do it again for  
16 or?  
17  
18 S: Em, (3) not very long. (1) Not very long at all  
19 really.  
20  
21 JM: Couple of days or (1) a week?  
22  
23 S: Yeah, could have been a week or two weeks or  
24  
25 JM: (1) Right, and did you notice any changes at all in,  
26 in (1) your lifestyle?  
27  
28 S: Errrr, (1) yes I have (1) noticed some benefit from  
29 using (.) Becotide or (.) Beclomethasone or you  
30 know?  
31  
32 JM: Yeah.  
33  
34 S: When I have taken it regularly there's been (1)  
35 some benefit from using it.  
36  
37 JM: Wh, what, which is?  
38  
39 S: (1) Em, (4) lessening of (.) asthma symptoms (1)  
40 basically. Em, (2) not quite as wheezy (2) but em,  
41 (2) I sort of find that (1) unless my asthma's really  
42 bad (1) which is usually when I've got a cold (1) or  
43 you know, whenever I get the cold I get a chest  
44 infection. (2) And (1) unless it's at peak times in  
45 the year i.e. summer (1) or when I've got a cold (2)  
46 my asthma is (1) or has been ((coughing)), sorry,  
47 up until the last three years (.) fairly (.) mild, if you  
48 know what I mean? Only in extreme times have I  
49 needed to use (1) em, any form of prev, (.)  
50 medicine. I mean there was a time where, in the  
51 winter (1) I didn't use ventolin in the winter at all.  
52 (1) Em, now I'm using it all the time (2) more so

1 in, as I say in summer and if I've got a cold. So  
2 what I tended to do (2), when my asthma was (1)  
3 milder in winter (1) and when I was well (1) I  
4 didn't use any (2) asthma preventative or reliever  
5 (1) and then at times when I was unwell (1) or in  
6 summer, I tended in the last, sort of six or seven  
7 years (2) to go with em, (2) go to the doctor with a  
8 chest infection and then it's just been a course of  
9 antibiotics which never work (1) cos I've had so  
10 much flucloxacillin or (2) amoxicillin I don't know  
11 what you know? Every time I go to the doctors  
12 with a cold (.) I get a chest infection. Get a chest  
13 infection you get bad asthma (1). If I run out of  
14 ventolin I need more ventolin and it's usually got  
15 to the stage where (.) the doctor will prescribe me  
16 prednisolone (1) er steroids eh, to boost me up  
17 again. (2) Or at times, seasonal times an  
18 antihistamine (2) and more ventolin, and that's  
19 how it's worked. It's sort of been a pattern of (.)  
20 not having many symptoms and not having any  
21 preventative or reliever (1) or very little reliever  
22 (1) and then (1) when the times come when I'm not  
23 well or seasonally in summer (1) I have (3) still no  
24 preventative medicine. Go and get prescribed it (.)  
25 from the doctor (.) knowing full well that I'm not  
26 going to take it (1). I don't know why.  
27  
28 JM: Did you initiate going to see the doctor for the  
29 preventative medication?  
30  
31 S: (2) What in, initially or?  
32  
33 JM: Sort of, em, em (1) well yeah both actually, I  
34 mean, I mean initially I guess they came up with  
35 (2) the idea to prescribe the brown inhaler, is that  
36 right?  
37  
38 S: Yeah. Yeah.  
39  
40 JM: And, and then (1), then after that you, it comes  
41 round to the summer (1).  
42  
43 S: Yeah.  
44  
45 JM: What would happen, w, would you, would think  
46 "right I'll go and get some preventative  
47 medication?"  
48  
49 S: Yeah. (1) Normally, usually around June time.  
50  
51 JM: Right.  
52

1 S: Sort of mid June (1) my asthma symptoms (1) get  
2 dramatically worse. (1) Em, (1) due to (.) grass  
3 being cut and  
4

5 JM: Yeah.  
6

7 S: pollens and (1) dust and everything else. (1) So (1)  
8 at that point (.) I sort of think, oh you know (.)  
9 usually get a summer cold (.) or my chest starts  
10 getting tight and I think “*oh (.) I’m getting low on*  
11 *ventolin*” so I go to the doctors and say (1) I’d say  
12 the last sort of three or four years (1) it was more  
13 then to get the antihistamines cos I found they have  
14 actually worked (1) quite a lot. (1) You know  
15 they’ve significantly (1) decreased the (1) asthma  
16 symptoms in summer. (1) Em, and I’ve sort of  
17 used those as a preventer (1) as such (1) and (.) I  
18 do take them because they do make a lot of  
19 difference ((said with mild chuckle)). (1) You  
20 know? Em, (1) I mean I’ve been prescribed with  
21 them again this year (1) for the summer (1) and I  
22 did take them and they did make a difference. And  
23 they usually do (.) make a difference. Em, whereas  
24 the (3) Becotide (1) I just get out of the habit of  
25 taking it. (.) I just (2), I’ve never forced myself (2)  
26 to get in the habit of taking it. (2)  
27

28 JM: So when you went along and you went to go and  
29 get ventolin and antihistamines, not specifically to  
30 get Becotide or, or whatever?  
31

32 S: No, no.  
33

34 JM: The, that would obviously come up and they’d  
35 prescribe it. Would you ever discuss (.) how you  
36 felt about that or?  
37

38 S: No, no, I’ve never really (2) said how I feel about  
39 it. I mean, I’ve, I’ve always sort of said (1) thought  
40 that I need some form of preventative medicine (.)  
41 at certain times in my life (3). As I say, at certain  
42 times of the year not needed any (1). Em, (2) but as  
43 I say you know when I (1) in recent times when  
44 I’ve gone to the doctors it’s because of I’ve been  
45 unwell (.) basically or the season, if its (.) summer  
46 and I’m unwell (2) so unless (2), unless I am bad I  
47 wouldn’t go to the doctors. Em, (2) or unless I was  
48 out of ventolin (.) I wouldn’t go to the doctors. (3)  
49 I mean several doctors over (2) a long period of  
50 time tried to get me to go to (1) asthma clinics and  
51 it’s not a case of (.), it’s not been made available,  
52 because it has, you know? (.) Every surgery that



1 I've been at has sort of said you know, (1) "we're  
2 *running an asthma clinic (1) every (1) whenever*  
3 *(2), would you like to attend you know can you*  
4 *come and attend to it?" (2) Which (2) I never*  
5 *really have, never sort of, you know?*  
6  
7 JM: Why? Why did you not want to?  
8  
9 S: Em, (1) I don't know really. I don't know (2). I  
10 don't know.  
11  
12 JM: (1) Just, I'm just interested in em, (.) you saying  
13 that you wanted to manage your, I mean how, is it  
14 only recently that you really (1) decided that you  
15 really wanted to manage your asthma?  
16  
17 S: Yeah, I mean [we read]  
18  
19 JM: [Or has it] (.) been like that you've not (1) done  
20 anything about it?  
21  
22 S: Em, (1) I suppose because it's been getting worse  
23 (1) over recent years (1) em, (2) whether it's partly  
24 the toll of me smoking (.) or (2), or what, I don't  
25 know. Or more stress because of the work  
26 environment that I'm now in. (1) Being self  
27 employed (2) or, or being married I don't know.  
28 ((laughter)) But, you know my, my asthma has got  
29 worse over the last sort of three or four years (1)  
30 and (2) yes I would like to control it better. (3) As I  
31 say you know, with, (2) with (.) and when we first  
32 heard about the eh, (.) this tablet, I don't know  
33 whether it's the same tablet we'd heard about em,  
34 (.) read it in a newspaper, saying that there was a  
35 new tablet coming out to (.) try and prevent asthma  
36 (.) or to cure, not cure asthma you know it's like  
37 this wonder pill for asthmatics (.) that might  
38 (.) have the answer and, my wife read it and  
39 showed it me and I thought "*now that's (1) that'd*  
40 *be handy*" you know what I mean? (1) If it actually  
41 worked.  
42  
43 JM: Mmmmm  
44  
45 S: Rather than taking the ventolin all the time or (.)  
46 trying to take the Becotide at various points or (.)  
47 antihistamines or steroids or, or what, you know?  
48 (1) Em, (.) and then as I say, I was contacted  
49 through the study (2) em, if I'd like to take part in  
50 this (2) study, I suppose.  
51  
52

1 JM: What sort of patterns were for[med]  
2  
3 M: [Which the the=  
4  
5 JM: =For both, wh what happened with ((? Sentence  
6 doesn't seem to finish))  
7  
8 (.)  
9  
10 M: Well the first, the first thing I when I was (.) when  
11 I went on the nebuliser I think I was given 10 times  
12 the dose that you would get from the inhaler (1) so  
13 at the onset I realised that (.) I mean within reason  
14 one puff in 4 hours weren't actually going to do me  
15 much good as way of relief (1) um and they did  
16 say that you know you really (.) are able to give  
17 yourself more than that if the symptoms demand it.  
18 (1) I mean for instance you have two puffs (.) but  
19 in any event you're getting 10 times the dose on  
20 your nebuliser (1) um so that was a comfort  
21 because obviously that is so so effective with me I  
22 really don't need to resort to th(h)o(h)se kind of  
23 doses it really is you know one puff perhaps two (.)  
24 um (.) and you feel the symptoms you know (1)  
25 um (.) diminishing (.) in half a minute (.) its s:o  
26 effective (.) and if its so effective you know (1)  
27 one wonders what the you know what the brown  
28 one is is um(.) what use that is the brown one you  
29 know if if I suppose in time you might even get  
30 immune to the(.) to the ventolin, the salbutamol.  
31  
32 JM: Has the nurse discussed that with you=  
33  
34 M: =No, no  
35  
36 JM: So y you did you did you actually take the brown  
37 one at all when you were given it or(.) did you just  
38 use the blue one  
39  
40 M: I did actually to start with and then °didn't do till it  
41 actually just was there but I didn't actually [(??)°]  
42  
43 JM: [What]  
44 what stopped you using it do you think?  
45  
46 M: ↓Probably(.) I don't really want to be hooked on  
47 these for the rest of my life sort of thing(.) possibly  
48 (.) um at the time I was going through um (.)  
49 problems with um (1) my eyes which I was under a  
50 cornea consultant (.) because um I got very itchy  
51 eyes and it um (.) was diagnosed (??) which um (1)  
52 at that time I you know was taking medication for

1 that (1) and obviously I need to have um (.) sort of  
2 the eczema controlled with um (.) I've got one  
3 cream that is magic on me but is obviously quite a  
4 strong steroid which isn't that essential um and  
5 again I (.) I was warned not to take that too  
6 regularly (nevertheless?) (.) fantastic does a good  
7 job and a couple of (.) couple of doses of that and  
8 the problem is gone for 10 days to a fortnight. SO I  
9 THINK IT WAS A:::LL THAT I I DON'T  
10 REALLY WANT TO BE HOOKED, DO I NEED  
11 TO BE HOOKED ON ALL THIS STUFF AND IF  
12 THERE IS ANYTHING I CAN DROP OFF  
13 °obviously I s'pose the beclonase was was one of  
14 them°.  
15  
16 JM: And did you go back to (.) the surgery and sort of  
17 discuss (.) the way you managing your asthma=  
18  
19 M: =No. Um (1) basically (.) I didn't (1) I didn't go  
20 back unt:il (.) um (1) ((trying to recollect)) how did  
21 I get involved with the asthma clinic? ((asking self  
22 the question)) I think it was the GP is saying (.) um  
23 was was looking at the number of times I had had  
24 the salbutamol on prescription (.) and saying I  
25 don't know whether they actually just got the  
26 asthma nurse or or (.) or whether (.) um she  
27 thought it was my an idea that they could be better  
28 managed than I was doing so at the time (.) that I  
29 saw the the asthma nurse and (.) um perhaps saw  
30 her a couple of times before (.) she rang me and  
31 said would you like to (.) y'know join the scheme.  
32  
33 JM: Right=  
34  
35 M: =So I have it has been. But I stress it is not a  
36 debili(.)tating (.) problem insofar as my (.) y'know  
37 °my work is concerned or my you know my life is  
38 concerned. (.) Um (.) I don't play (.) football I do  
39 (.) occasionally bouts of strenuous work (1) um but  
40 its managed° and I'm very fortunate in that (.) you  
41 know I can choose (in the middle?) ((of  
42 something?)) what what I do (.) a- at work rather  
43 than (.) um (.) you know being in a managerial  
44 position I mean I don't wanna (1) y'know er (2)  
45 brag but you do have a little bit of flex(h)ib(h)ility  
46 um and if there's you know y'know there's  
47 somebody else available who will move the grain  
48 lorry up and you know I would do his job while he  
49 did while he did that (.) and if its unavoidable well  
50 I (.) I'll do you know put a mask on and move the  
51 lorry myself which is its not an issue as far as I'm  
52 concerned (1) you know the guy um (.) you know I

1 can certainly ask somebody else can you just move  
2 down (.) while I take over from you= =Everybody  
3 knows that the reason I'm doing it I'm not  
4 frightened of work but they just (.) I can manage it  
5 in that way (.) um (.) so (.) I suppose you could say  
6 well actually you are changing your lifestyle but  
7 not to that degree.  
8  
9 (1)  
10  
11 JM: Um (.) Um when you entered the study (.) and you  
12 were randomised to the (.) brown inhaler=  
13  
14 M: =↑Mmhm  
15  
16 (1)  
17  
18 JM: did the nurse talk about how she would like use it=  
19  
20 M: =Yes  
21  
22 JM: °What did she say°  
23  
24 M: She said morning and night  
25  
26 (.)  
27  
28 JM: °What did you say°  
29  
30 M: I said fine. if its part of the study, of course I'll do  
31 it  
32  
33 JM: And and [have]  
34  
35 M: [And ] I have been doing it  
36  
37 JM: °And how long's that been, how long have you  
38 been on it°  
39  
40 (1)  
41  
42 M: With the study you should have the de↑tails of  
43 that=  
44  
45 JM: =I have but its in my car=  
46  
47 M: =Right [okay]  
48  
49 JM: [hh ]  
50  
51 M: um its probabl::y (1) err  
52

1 JM: It's a few weeks is it  
2  
3 M: I think I've got it in my diary but its been going  
4 just before Christmas was it?=  
5  
6 JM: =How's it been going  
7  
8 M: Absolutely fine yeh I haven't missed a I haven't  
9 missed a (.) um (.) you know a preventative dose?  
10 (2) °I'm quite disappointed (??)°. (.) I mean I I  
11 have been as religiously as I possibly can, (1) if the  
12 study is going to have any value you don't  
13 particularly want people doing their own thing if  
14 you've been told to take it °twice a day then you  
15 take it twice a [day°]  
16  
17 JM: [And] you're happy with that=  
18  
19 M: =↑Of course, (1) its part of the survey and if it does  
20 (.) I mean if it MAY IF IT ISN'T DOING ME  
21 ANY GOOD WELL (.) AT LEAST ITS DATA  
22 FOR SO(h)MEBOD(h)Y EL(h)SE TO MAKE A  
23 DECISION of whether its doing me any good.= I  
24 must admit WHEN WHEN my number was called  
25 out (.) I think there is a there is another group  
26 taking um tablets isn't there (2) ((perhaps non-  
27 verbal confirmation from D)) I WOULD HAVE  
28 LIKED TO TRY THAT °but it wouldn't make any  
29 difference° (3) I was you know I said I was happy  
30 to do the survey and (1) if it involves standing on  
31 your on one leg and hopping round before you take  
32 it I mean that's you know that's what you sign up  
33 to do isn't it.  
34  
35 JM: Have you noticed any differences?  
36  
37 M: Well I haven't had any symptoms since I must  
38 admit (.) um it isn't a kind of a (.) polleny type of  
39 season (1) um (2) I haven't (2) if I'm taking the  
40 Ventolin since I've been on the survey if I've only  
41 taken the Ventolin twice °with the brown inhaler  
42 that's the up side (1) and that was probably one  
43 evening when I'd got another you know a cold (2)  
44 but um° (1) WHETHER OR NOT (2) ITS EARLY  
45 DAYS but I mean as far as I can see yes I mean its  
46 obviously reduced the need to take the (.) to take  
47 the (.) curative.  
48  
49 JM: As you say its early days but do you (.) do you  
50 think that um (1) the benefits outweigh (.) the °you  
51 were sort of saying earlier that you didn't want to  
52 be hooked on [ ((too many medications??))° ]

- 1 D: Yes I wrote about I think I think I did I wrote about  
2 walking up a hill oh yes walking up a hill sleeping  
3 all night and um (.) being able to go round peoples  
4 who've got animals (.) which live indoors  
5
- 6 JM: And have things changed with those?  
7
- 8 D: Well I haven't really walked up steep hi(h)lls s(h)o  
9 I don't kn(h)ow heh heh but a- as for the sleeping  
10 better a night yes they have changed I haven't been  
11 waking up coughing (.) and had this irritation in  
12 my throat so much during the night that has got  
13 better (.) but I haven't been round anybody's with  
14 animals either since I've been taking it so I don't  
15 know about those two.  
16
- 17 JM: °Okay°. How would you say your um how would  
18 you describe your asthma would you is it does it  
19 stay pretty much constant or does it change a lot  
20 from day to day?  
21
- 22 D: No it stays pretty much constant really (.) yeah no  
23 that doesn't (.) that doesn't change (.) only if I get  
24 as I say if I get a bad cold or anything like that it's  
25 the only time that change or um (.) PERHAPS IF I  
26 GET IF I GET REALLY STRESSED out about  
27 something (.) that'll that will change (.) y- you  
28 know I'll find that um the chest will tighten up and  
29 I'll need to use it if I get really stressed about  
30 something (.) but apart from that that's sort of just  
31 stays the same really  
32
- 33 JM: °Okay°. How how much um at risk do you do you  
34 feel do you (.) um (.) do you feel that (.) is is do  
35 you think about asthma everyday is it so[me]thing  
36
- 37 D: [No] I  
38 don't think about it no I don't feel at risk really  
39 with it at all  
40  
41 (1)  
42
- 43 JM: Okay ((said as if 'never mind lets try another  
44 angle')) um and you what habits do you have with  
45 your blue inhaler, do do you have that with you  
46 everyday or?  
47
- 48 D: Yes I always have one in my bag I always take  
49 have one with me. I have one laid I I've got, I  
50 always have one beside my bed and um I do I do  
51 carry one about with me just in case  
52

1 JM: Okay  
2  
3 D: But I never use it (.) well touch wood °heh heh  
4 heh°  
5  
6 JM: Do do you always have more than one in (.) one  
7 blue inhaler or do you have do do you make sure  
8 how how if you run out of a blue inhaler um when  
9 would you go and renew a prescription when you  
10 have none left or?  
11  
12 D: No I I try and keep two so I can leave one beside  
13 the bed and keep one um when one gets when one  
14 is virtually run out um (.) I just >go and get another  
15 one< (.) I just phone up I just because I get them  
16 on repeat prescription anyway (.) so I just  
17  
18 JM: Do they ever talk to you about when how often do  
19 you go for a review visit  
20  
21 D: I don't. Heh heh heh heh no I don't go for asthma  
22 review visits at all  
23  
24 JM: Do they invite you to come for a review  
25  
26 D: NO THEY HAVEN'T NO that's usually if I go for  
27 something else he would say "oh that's about time  
28 we did something about your asthma" OR if um if  
29 the prescription if the prescription runs out (.) you  
30 know because you have they only give you sort of  
31 like six months don't they and then I'll go and (.)  
32 but um (1) its usually when I've been for  
33 something else (2) cos um I have to go to review  
34 for review for my (.) thyroid so he used to he used  
35 to (just?) do both at the same time  
36  
37 JM: mm  
38  
39 D: um and er doesn't really do much just get me to  
40 blow in the tube and I'm no different that I e(h)ver  
41 a(h)m  
42  
43 JM: And does he ask you any questions about your  
44 asthma?  
45  
46 D: Yeah he usually asks me you know some (1) if I've  
47 if I've got worse or you know if that's troubled me  
48 very much and things like that but (.) not  
49 specifically  
50  
51 JM: And and (.) the (.) um do you talk to him about  
52 how you use (.) the brown inhaler we talked about

1 that briefly before um (.) and he said that you  
2 should take that (.) to did he say that you should  
3 take that every day or (.) a long period or did he  
4 how did he say you should use it over a long  
5 period of time (.) cos you sort of mentioned did  
6 you mention to him that you stopped using it  
7

8 D: Yes yeah (1) ahhh well he sort of (.) hhh  
9 ((sounding slightly exasperated with questioning))  
10 I mean his advice is really that I should use it (.) all  
11 the while and its totally down to me that I don't  
12 because his advice to me is (.) to use it (.) y'know  
13 most of the time but I mean I feel fine (.) without it  
14 I don't really know why I need to use it because  
15 without using it (.) I'm alright I don't get  
16 breathless or get any asthma symptoms  
17

18 JM: And do do you actually share that view with him or  
19

20 D: Yes he know I stopped using it yes yeah (.) spose  
21 he just you know he just (.) said you know if I you  
22 know its up to you really (??) SO I I MEAN IF I'M  
23 IF I'M do have a bad attack alright I will start  
24 using it (1) for any reason um (.) have a bad attack  
25 but (.) normal run of the day things I don't (.) I  
26 don't want to use it (.) hh every day  
27

28 JM: I'm just trying to understand why exactly (hhh)  
29 ((slightly nervous laughter))  
30

31 D: WELL I I DON'T KNOW I THINK ITS JUST AS  
32 I SAY ITS JUST THE THOUGHT OF TAKING  
33 IT EVERYDAY WHEN I DON'T REALLY  
34 FEEL I NEED IT  
35

36 JM: °Okay that's fine° um okay that that's (.) that's  
37 great um I just wonder when you've been out in  
38 public you carry do you take your blue inhaler with  
39 you have you ever been out and realised you've  
40 not had it  
41

42 D: What and panicked? (1) No. Only that one time in  
43 New Ze(h)ala(h)nd  
44

45 JM: [heh heh]  
46

47 D: [heh heh] wh(h)en I nee(h)ded it and I didn't have  
48 it with me ehm no no no I don't normally panic or  
49 think that I haven't got it and worried about it (.)  
50 no.  
51



1 JM: So what what would you do in that situation just  
2 carry on?  
3  
4 D: Just carry on once I've sat down 10 minutes or so  
5 and got me breath back um you know I'm alright  
6  
7 JM: Okay (.) um (.) does does carrying using blue  
8 inhaler inhalers in public is that is that a problem  
9 or is that  
10  
11 D: No it wouldn't bother me no.  
12  
13 (2)  
14  
15 JM: Um (.) okay do you know anybody else with um  
16 asthma (1) °is there° anybody you know at all?  
17  
18 D: Do I know anyone else with asthma?  
19  
20 JM: Anyone else? any of your friends or family?  
21  
22 D: Yes a girl over the road has got it she's got hay  
23 fever and asthma yeah  
24  
25 JM: Do you often talk about it with her or?  
26  
27 D: Not really she's really bad she has to have  
28 injecti(h)ons and ev(h)erything heh heh  
29  
30 JM: Really  
31  
32 D: (??) injections  
33  
34 JM: How do you compare her asthma to yours  
35  
36 D: Terrible I mean you know I mean mine is nothing  
37 you know mine doesn't affect me at all compared  
38 to how she is  
39  
40 JM: So is does she have she's diagnosed with asthma  
41 and and uh would (.) you would you consider that  
42 your symptoms are very different to hers  
43  
44 D: Um (2) I don't really know I mean mine is  
45 nowhere near as severe as hers (2) um different (.)  
46 no I don't suppose they're that much different they  
47 are just a lot milder form I mean hers is much more  
48 severe mine is just so mild compared to how she  
49 suffers yeah.

- 1 J: Oh a week a couple of weeks I suppose, week  
2 couple of weeks I suppose what you know you can  
3 (??) the difference  
4
- 5 JM: Right  
6
- 7 J: Not saying I was right but you could feel the  
8 difference  
9
- 10 JM: Right okay so when you first took the brown  
11 inhaler you didn't notice the difference straight  
12 away  
13
- 14 J: Not straight away but a few days to a week I  
15 suppose and then you'd notice the difference  
16
- 17 JM: Okay what what about the blue inhaler  
18
- 19 J: Well more or less the same as th↑at I think (2)  
20 yeah  
21  
22 (2)  
23
- 24 JM: So they both take a week or two weeks  
25
- 26 J: Well well about a week I should think  
27
- 28 JM: Right (1) okay. What did the doctor say about how  
29 the two different treatments work did he explain  
30 anything?  
31
- 32 J: Well he just said um to take the brown one  
33 morning and night and then take the blue one  
34 during the day during the day sort of thing when I  
35 have to take it  
36
- 37 JM: And did he say how what they do?  
38
- 39 J: Yeah he said they sort of you know will help you  
40 and he said I could take I think I could take the  
41 brown one once more during the day but if I want I  
42 could take the blue one during you know more  
43 during the day  
44
- 45 JM: Mm and you and you think it made sort of about a  
46 week two weeks  
47
- 48 J: Yeah about a week  
49
- 50 JM: So you can you describe sort of what sort of habits  
51 you got into with your inhalers  
52

1 J: ↑Oh I just used to make sure I got one both with  
2 me when I went out, they were in me bag or  
3 whatever I'd got and use to make I've always got  
4 one one of each beside me bed anyhow and always  
5 used to make sure I got one with me when I ↑went  
6 out ((rising intonation said as if this was no big  
7 deal))  
8  
9 JM: Right and you you sort of said that um you didn't  
10 use it everyday  
11  
12 J: No  
13  
14 JM: Your inhaler um again I'm not here to sort of say  
15  
16 J: No  
17  
18 JM: why aren't you using it but why did you decide not  
19 to or why did you decide  
20  
21 J: Well I think I probably I did forget to take it first  
22 thing in the morning sort of thing I think that was  
23 half of it and you know if you felt alright you sort  
24 of didn't think to take it it weren't not very often  
25  
26 (3)  
27  
28 JM: Ok. Um and have you been did you go back to the  
29 doctors after?  
30  
31 J: I think I probably had to go back to check that  
32 everything you know was alright I'm sure I did.  
33 He wanted to check you know to make sure it was  
34 alright (1) yeah  
35  
36 JM: And what did he say do you remember  
37  
38 J: He said that was y'know sort of carry on with your  
39 inhalers and y'know take them how you should  
40 sort of thing  
41  
42 JM: You say you've been doing that for about 30  
43 years?=  
44  
45 J: =°Yeah°  
46  
47 JM: (??) um okay and the first time you changed was  
48 when you entered this study  
49  
50 J: Yeah  
51

1 JM: What made you um decide to take part in the study  
2 was there  
3  
4 J: Well I I think I don't know if I had a letter or they  
5 rung me up  
6  
7 JM: Yeah  
8  
9 J: And I said providing that worked round me sort of  
10 thing I could do it  
11  
12 JM: And you were happy to try something different  
13  
14 J: Yeah  
15  
16 JM: And um so you've been taking the tablet for  
17  
18 J: A couple of weeks I think (1) I think I'm on the (1)  
19 cos there's four strips I think in the packets I think  
20 I must be now on the third strip  
21  
22 JM: Right  
23  
24 J: something like that  
25  
26 JM: And how's that going  
27  
28 J: Alri↑ght yeah  
29  
30 JM: You're sort of  
31  
32 J: I think I've got to go and see her again oh I forget  
33 I've got it in my diary  
34  
35 JM: It's a few weeks wasn't it  
36  
37 J: Yeah.  
38  
39 ((searches in bag for diary))  
40  
41 JM: That's alright don't worry it's a few weeks isn't it  
42  
43 J: Yeah that is the 20<sup>th</sup> it's when I'm starting a new  
44 job I think  
45  
46 JM: yeah  
47  
48 J: I'd better tell them I might be a bit late well I aint  
49 gonna be long here about half an hour  
50  
51 JM: Yeah  
52

1 J: I've only got to go a little way up there so it aint  
2 far away  
3  
4 JM: that's handy  
5  
6 J: Yeah  
7  
8 JM: Um but you manage to remember to take it every  
9 [day or]  
10  
11 J: [Yeah] (1) well I try to heh heh heh  
12  
13 JM: Yeah. How would you compare the tablets with the  
14 inhalers  
15  
16 (3)  
17  
18 J: Al. Alri↑ght  
19  
20 JM: Do you think there's any differences?  
21  
22 J: Er (2) they don't seem to have no side effects or  
23 something (2) so long as I remember you know try  
24 to keep remembering to take one you have to to  
25 take one at night don't you  
26  
27 JM: Yeah  
28  
29 J: Yeah  
30  
31 JM: And how do you think they work do you feel that  
32 they work  
33  
34 J: Ye↑ah. (2) Yeah  
35  
36 JM: How have you noticed just how long it takes sort  
37 of thing  
38  
39 J: Um. .hhhh hhhhhh um no I took them I take them  
40 alright and they I seemed alright y'know after I  
41 took them and that so  
42  
43 JM: But, you said you mentioned the brown inhaler  
44 took about a week two weeks  
45  
46 J: Yeah I think that was when I first had it I suppose  
47 to get use you know  
48  
49 JM: Get used to it  
50  
51 J: Yeah get used to them  
52

1 JM: And then the tablet have you noticed any  
2 difference how long do you think that took to work  
3  
4 J: Oh it must be oh (1) well just under a week I  
5 suppose yeah  
6  
7 JM: And has anything changed in in your life that you  
8 like do you do more or  
9  
10 J: No about the same I think, mind you I have had a  
11 lot of hassles just lately so that's probably not  
12 helped so heh [heh heh] heh  
13  
14 JM: [Really]  
15  
16 J: So, going through a bad patch yeah  
17  
18 JM: Yeah  
19  
20 J: Work and home so  
21  
22 JM: Right  
23  
24 J: That didn't help  
25  
26 JM: So that's not helped your asthma  
27  
28 J: Well it weren't it weren't too good you know it  
29 weren't too bad I just you could feel it sort of you  
30 know coming on sort of thing  
31  
32 JM: Do you think there's um do you think there's a link  
33 between sort of what happens in your life and your  
34 breathing  
35  
36 J: Yes sometimes, I wouldn't say all the time but  
37 sometimes yeah  
38  
39 JM: In what way do you think  
40  
41 J: Well you just get tense and that sort of (1) you  
42 know start coughing or something like that and it  
43 sort of bring it on  
44  
45 JM: Really, a lot of people say that  
46  
47 J: Um well (1) I don't know heh heh heh  
48  
49 JM: no [(??)]

1 F: cos normally you don't know when you're going to  
2 be suddenly doing something sort of quite physical  
3 so you do get caught out  
4  
5 JM: Did you get invited to go back to the surgery to  
6 discuss your asthma attack?  
7  
8 F: Yes not no only seen the asthma nurse  
9  
10 JM: Right so not up until that point  
11  
12 F: No  
13  
14 JM: Do you ever think about going back to speak to  
15  
16 F: Well no because I just thought well you know  
17 everybody's got asthma and it seems such a  
18 common thing and um quite frankly you don't feel  
19 ill you know that's the thing you don't feel ill as  
20 such just the fact you can't breath do you see what  
21 I mean you don't its not like you've got a cold or  
22 you've got the flu anything like that you haven't  
23 you you're perfectly okay apart from the fact you  
24 can't you're gasping for breath so sometimes  
25 I'll feel a bit of a fraud for for (??). In fact I went  
26 in there one time and said doctor I feel alright and  
27 he said out straight away that's because me ears  
28 were playing me up  
29  
30 JM: When was that  
31  
32 F: That was a couple of years ago um cos he's quite a  
33 nice doctor well I think he is he always eats  
34 sweets, never got a tie on you walk in and he says  
35 hello ((name)), how's ((wife's name)) (??) the wife  
36 which is nice but, um no so ah I just use the blue  
37 one (??) about the brown one.  
38  
39 JM: Just thinking about you don't feel uh being out of  
40 breath is is or is an illness  
41  
42 F: No I I don't know  
43  
44 JM: How would you describe your obviously doctors  
45 say you have asthma  
46  
47 F: Yeh  
48  
49 JM: How would you how do you feel about  
50  
51 F: What, having asthma  
52

1 JM: Or what do do its just that asthma is defined as an  
2 illness  
3  
4 F: Yeh, yeh  
5  
6 JM: But you feel that you don't really feel ill  
7  
8 F: No um  
9  
10 JM: I'm just trying to understand how you sort of see  
11 yourself  
12  
13 F: Well I suppose perhaps because my grandmother  
14 had asthma and the number of times we used to  
15 have to rush to hospital and take my mum and dad  
16 uh because she was on death's door and I (??) and  
17 she had a once (??) pump something into her (??)  
18 and I suppose because I saw her like that it didn't I  
19 didn't associate it with being an illness as such it  
20 was just the fact that some people have a job to  
21 expel their air or whatever, that's how I looked at  
22 it. Um and as I say if this chap on ((company  
23 name)) hadn't said to me you know you ought to  
24 get it sorted out because you shouldn't be like that  
25 um I probably would have carried on cos its just  
26 one of those things some people have got that um  
27 some people lose a hand you know its just  
28 something that happens and um you've got to live  
29 with it.  
30



*Excerpt 8: Data-Sharing Focus Group, pages 26- 29; Adult Education Centre*

1 P3: around me used to smoke all day cos there was no  
2 such thing as no smoking at work  
3  
4 P6: mm  
5  
6 P3: In them days  
7  
8 P6: mm  
9  
10 P3: It's different now intit.  
11  
12 P6: mm  
13  
14 P3: And I used to find  
15  
16 P6: mm  
17  
18 P3: with the smoke around me I used to find that used  
19 to bring it on perhaps that was what it was I don't  
20 know  
21  
22 P5: Once it started then its its  
23  
24 P3: that's right yeah  
25  
26 P5: Only the treatment to control it because if you  
27 hadn't been in that environment to start with you'd  
28 probably never have suffered  
29  
30 P3: No might not have [done] no.  
31  
32 [no ]  
33  
34 P3: mmm when I first started work there was no such  
35 thing no smoking not in work places [heh heh]  
36  
37 P6: [↑No: No] No  
38 (2) that was so you you er you welcomed the  
39 legislation  
40  
41 P3: Oh yes I did yeah  
42  
43 ALL: heh heh heh  
44  
45 P3: Yes I can't I can't handle smoke  
46  
47 P2: no no  
48  
49 P3: being round me at all  
50  
51 P2: no  
52

1	P3:	No I can't no (2) mm
2		
3	P6:	yeah (2)
4		
5	JM:	Ok I've got one more ((passes round 4th vignette))
6		
7	P5:	It's surprising when you think of the old days
8		when you used to go to the cinemas and there'd be
9		somebody in front of you [smoking] (??)
10		
11	P3:	[puf(h)ing] aw(h)ay heh
12		heh yeah
13		
14	P5:	I suppose with the modern generation course they
15		don't get these problems do they really
16		
17	P3:	n:o
18		
19	JM:	Ok this one says "I don't think I have asthma. I
20		think doctors and nurses do not understand my
21		symptoms and I don't feel that they listen when I
22		go to see them or talk about the causes of asthma
23		properly. I am concerned about the side-effects of
24		medications. The experts say that some
25		medications are now unsafe so I don't want to take
26		a medication everyday that I don't think works
27		very well."
28		
29		(11)
30		
31	P6:	Well I feel sorry for em they
32		
33		(7)
34		
35	P1:	Well I was lucky when I went to see the nurse she
36		actually suffered from asthma which was great
37		because she knew exactly what I was talking about
38		and what I should do and shouldn't do and I seem
39		to remember she said there were no side-effects
40		from the brown one but the blue one be careful
41		with the blue one seem to remember her saying
42		
43		(2)
44		
45	P6:	Oh I didn't know tha:t
46		
47	P5:	What is the compound difference then between the
48		brown and the blue one
49		
50	P1:	The bro[wn one coats]
51		

1 P6: [used to be ]ventolin but it's sort of  
2 salbutamol int it  
3  
4 P1: mm the brown one coats the lung don't it though  
5 and stop irritation and the blue one opens the opens  
6 the bronchial tubes up  
7  
8 (2)  
9  
10 P6: mm but the I don't know whether I was (2)  
11 completely awake at the time but I thought when  
12 they when they hook you on to a nebul a nebuliser  
13 I don't know if that has happened to any of you but  
14 you're getting 10 times the dose of the blue one so  
15 it really is a really is a kick in the system  
16  
17 P1: mm  
18  
19 P5: mm  
20  
21 P6: Um but that I may have got that wrong but you got  
22 the blue one you do have a puff on the blue one but  
23 actually when hooked on to a nebuliser you're  
24 actually going to get 10 times the dose um the blue  
25 one in theory can't be that harmful can it not your  
26 blue puffer if that's the case  
27  
28 P1: mm  
29  
30 P6: particularly if you are only doing it odd occasions  
31  
32 P1: mm  
33  
34 P3: mm  
35  
36 P6: I think we get hung up on these side-effects  
37 sometimes because you got side-effects with  
38 aspirin as well  
39  
40 P3: that's right [side effects on anything ]  
41  
42 P6: [every day you take the balance] so if I  
43 do this little bit of side-effect  
44  
45 P6: but if I don't=  
46  
47 P3: =°but° yeah that's right  
48  
49 P4: which is the worser of the two evils  
50  
51 P3: [that's right]  
52

1 P6: [indeed ]you're right you're right you've gotta  
2 fill up your car with petrol so you just have to go to  
3 the petrol station you know so you know that's a  
4 side-effect in effect it's a balance isn't it  
5  
6 P1: mm mm mm  
7  
8 P6: do I walk or run?  
9  
10 P1: I have I must admit I have I went to a chemists  
11 because I was suffering terribly from a cold I said  
12 to him I happened to know her she knew I suffered  
13 from asthma and she said "you wanna take  
14 Echinacea" and ever since I've taken Echinacea I  
15 don't take it all the time, I don't suffer from colds  
16 anymore  
17  
18 P6: Echi?  
19  
20 P1: Echinacea natural root I think natural it's a herb  
21 [its not its not its not a drug]  
22  
23 P5: [yeah. Echinacea you take it] as the symptoms of a  
24 cold is coming [don't you]  
25  
26 P1: [yeah]  
27  
28 P5: and er (??)  
29  
30 P1: but for me it seems to work  
31  
32 P6: hmm  
33  
34 P1: But she said drops were the best drops in a glass  
35 and just drink it so for me [(??)]  
36  
37 P5: [yeah] I've heard quite a  
38 lot of people say Echinacea is very good  
39  
40 P1: yeah  
41  
42 P6: °How do you spell that?°  
43  
44 ALL: heh heh [heh]  
45  
46 P3: [It is a natural] herb it's not a  
47  
48 P5: Ech is it  
49  
50 JM: ((To Ps 2 and 3, could not get eye contact)) What  
51 do other people think about the statement on the "I  
52 am concerned about the side-effects of

## Appendix C

### Recruitment of patients into the ELEVATE Study

#### **C.1. Extract from final report documenting recruitment procedure and selection criteria (Price et al., in press, pp. 18-22)**

##### *2.1 Participants*

In the BTS Guidelines on the Management of Asthma<sup>63</sup> the therapy of patients from age 6 up follows the same strategy as for adults except for alterations in dosage ranges to adjust for differences in body mass. Since exactly the same strategy is used across the age range of older children and adults, the findings of studies will have greater generalisability if they enrol patients from that entire range. Due to limitations of validity of the Mini Asthma Quality of Life Questionnaire and the Asthma Control Questionnaire (ACQ) we were unable to study children below the age of 12 but did allow children over this age as well as adults of all ages to be included to maximise generalisability of the study findings.

In the initial design of the study, participant recruitment was to be by primary care practice staff as they conducted acute and routine respiratory care visits, identifying patients who met the entry criteria, informing them of the study and, if appropriate, consenting and enrolling them into the study. Recruitment by this strategy was slower than originally anticipated due to changes in clinical practice resulting from delays in study funding and changes in national asthma guidelines. The protocol and the process of identification of eligible patients were therefore modified as described below to allow prospective identification of possible study participants. All patients entering the study met the same eligibility criteria and follow up was identical.

Further recruitment into the study was via a three-stage process.

##### *Recruitment Stage 1*

Patients aged 12 to 80 attending 53 participating primary care (or general) practices in Norfolk, Suffolk, Essex, Cambridgeshire, Bedfordshire, Hampshire, and Dorset and

who had received a prescription of short-acting  $\beta_2$  agonist in the previous 2 years were invited by letter to provide data allowing eligibility for the studies to be determined. Patients were asked to provide information on their current asthma status and inhaler usage. The case notes of patients whose asthma status was consistent with eligibility in the study were reviewed by practice and study staff against the following eligibility criteria:

**Inclusion criteria:**

- a. Capable of understanding the study and study procedures (and parent/guardian's capability of understanding the study and study procedures for patients aged under 16 years).
- b. Patient had a diagnosis of asthma (defined as: i) documented reversibility after inhaled short-acting  $\beta_2$  agonist AND/OR ii) PEF variability on PEF diary AND/OR iii) physician diagnosed asthma AND/OR iv) physician diagnosis of asthma plus history of response to treatment).
- c. Step 2 trial: patient was not currently receiving, and had not received inhaled steroid or leukotriene antagonist within the previous 12 weeks
- d. Step 3 trial: 1) patient had received inhaled steroid for at least the last 12 weeks, as ascertained from prescribing records and patient self-report, and 2) had not received a long-acting  $\beta_2$  agonist or leukotriene antagonist in the previous 12 weeks.

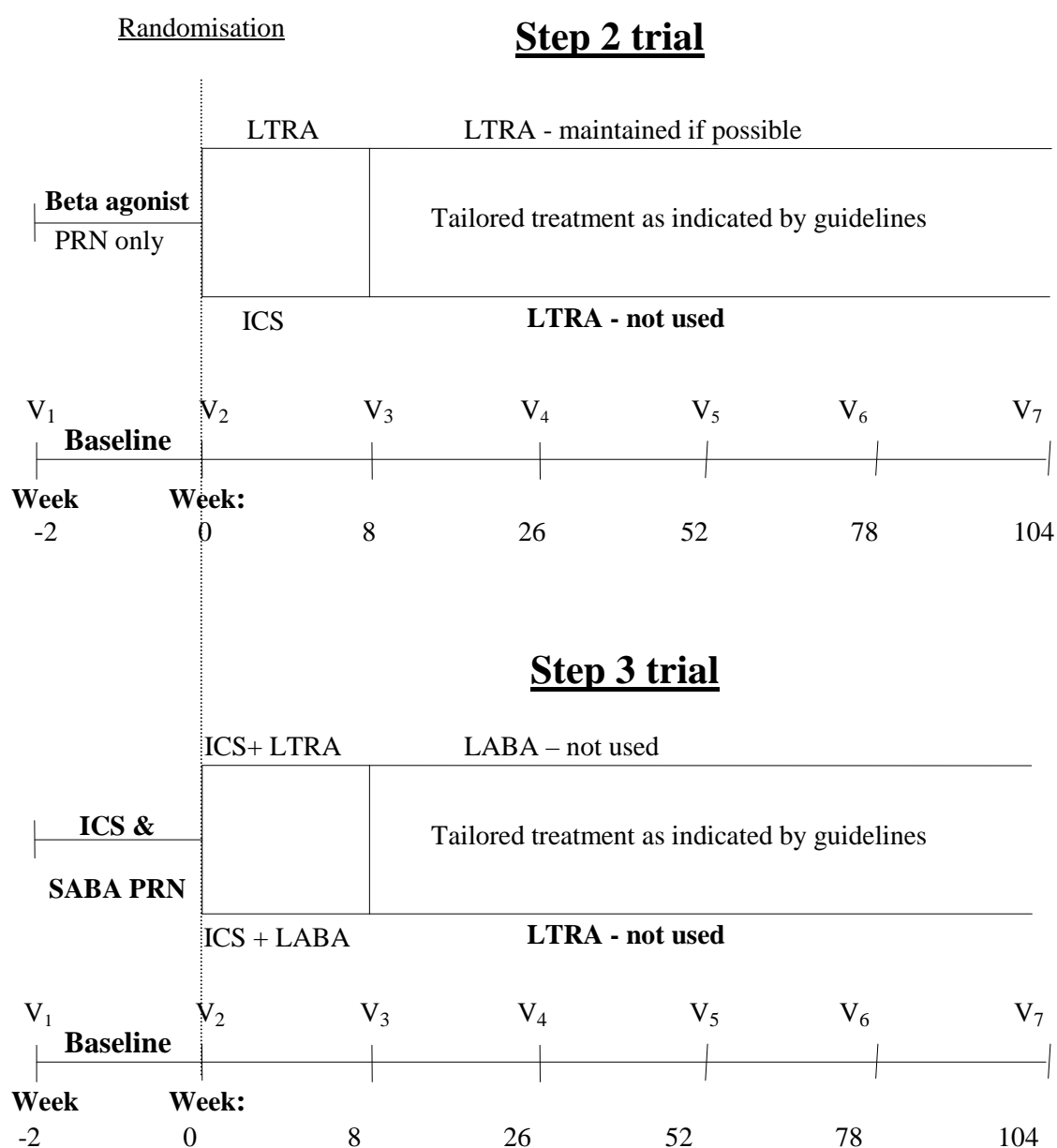
**Exclusion criteria:**

- e. Patient had participated in a clinical trial involving an investigational or marketed drug within 90 days.
- f. Patients had received a substantial change in anti-asthma medication within the previous 12 weeks.
- g. Patient was a current, or recent past abuser (within past 3 years), of alcohol or illicit drugs.
- h. Patient had any other active, acute or chronic pulmonary disorder or unresolved respiratory infection within previous 12 weeks.
- i. Patient had a history of any illness that was considered to be immediately life threatening, would pose restriction on participation or successful completion of the study, or would be put at risk by any study drugs (e.g., allergy to leukotriene antagonist).

- j. Patient had received systemic, intramuscular or intra-articular corticosteroids within the previous 2 weeks (artificial baseline).

Patients who met those entry criteria that could be assessed by a records review in their general practice were invited for a screening visit (visit 1; see Figures 1 and 2). All patients had at least 24 hours to review the patient information sheet prior to attending the visit. Patients attending for at least visit 1 will from here on be referred to as participants.

**Figure 1. Study Flow Charts:** Patients at step 2 received initial controller therapy with leukotriene antagonist or inhaled steroid. Patients at step 3 received leukotriene antagonist or long-acting  $\beta_2$  agonist as add-on to inhaled steroid



**Key**

ICS: Inhaled corticosteroids

LTRA: Leukotriene receptor antagonist

LABA: Long acting  $\beta$ 2-agonist

SABA: Short-acting  $\beta$ 2-agonist

***Recruitment Stage 2***

At visit 1, participants (and parent or guardian if appropriate) gave written informed consent and were allocated a unique study number. Participants were reviewed for the following additional entry criteria:

- a. PEF while withholding  $\beta$ <sub>2</sub>-agonist for at least 4 hours, of >50% predicted.
- b. Females of child bearing potential agreed to use adequate contraception throughout the study.

Participants meeting the above criteria completed a 2-week PEF diary, Asthma Control Questionnaire (ACQ), and asthma specific quality of life questionnaire (MiniAQLQ) prior to returning for visit 2.



**Figure 2. Time lines for both Step 2 and Step 3 trials.**

Visit → Study timescale in weeks → Leeway allowed in days →	BASELINE		TRIAL PERIOD				
	1	2	3	4	5	6	7
	-2	0	8	26	52	78	104
		+/- 7	+/- 21	+/- 21	+/- 21	+/- 21	+/- 21
<b>General practitioner and/or practice asthma nurse procedures</b>							
Assess inclusion/exclusion criteria	X						
Informed consent	X						
Record clinical/asthma history & prior medications		X					
Review clinical data& asthma therapy (per clinical need)	X	X	X	X	X	X	X
Check patient has/can adequately use PEF meter	X						
Treatment arm randomisation by dial-up centre		X					
Review action plan for worsening asthma	X	X	X	X	X	X	X
Review any adverse experiences		X	X	X	X	X	X
Record PEF (no inhaled β-agonist for 4 hours if possible)	X	X	X	X	X	X	X
Confirm patient resource utilisation		X	X	X	X	X	X
<b>Blinded research assistant / Study Office</b>							
Collect completed patient symptom diary card		X	X	X	X	X	X
Collect data on patient costs		X	X	X	X	X	X
AsthmaQOL & EuroQOL (Quality of Life) Questionnaires		X	X	X	X	X	X
Rhinitis questionnaires		X	X	X	X	X	X
Dispense patient diary card for subsequent visit	X	X	X	X	X	X	
Collect resource use data from practice records							X

### ***Recruitment Stage 3***

At visit 2, participants scoring  $\geq 1$  on the ACQ (range 0 to 6, with  $\leq 0.75$  being optimal<sup>67</sup>) and/or  $\leq 6$  (out of a maximum best score of 7) on the MiniAQLQ were registered and randomised within the step 2 or step 3 study by an automated “dial-up” centre at the University of East Anglia. A computer responded to calls from practices by recording identification information. It then used input from the practice about the step at which the patient was to enter the study to perform a lookup into predefined tables of randomisation allocations (see 2.6) and then inform the caller of the allocation for that participant.

## C.2. ELEVATE Screening Questionnaires

### MINI – Asthma Quality of Life QUESTIONNAIRE for age 12+ ©

#### The ELEVATE Study

Patient Initials

Study ID Number

Date

**Circle** the number that best describes how you have been during the past 2 weeks **as a result of your ASTHMA**

In general, how much of the time **during the last 2 weeks** did you:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
1. Feel <b>short of breath</b> as a result of your asthma?	1	2	3	4	5	6	7
2. Feel bothered by or have to avoid <b>dust</b> in the environment?	1	2	3	4	5	6	7
3. Feel <b>frustrated</b> as a result of your asthma?	1	2	3	4	5	6	7
4. Feel bothered by <b>coughing</b> ?	1	2	3	4	5	6	7
5. Feel <b>afraid of not having your asthma medication available</b> ?	1	2	3	4	5	6	7
6. Experience a feeling of <b>chest tightness or chest heaviness</b> ?	1	2	3	4	5	6	7
7. Feel bothered by or have to avoid <b>cigarette smoke</b> in the environment?	1	2	3	4	5	6	7
8. Have <b>difficulty getting a good night's sleep</b> as a result of your asthma?	1	2	3	4	5	6	7
9. Feel <b>concerned about having asthma</b> ?	1	2	3	4	5	6	7
10. Experience a <b>wheeze</b> in your chest?	1	2	3	4	5	6	7
11. Feel bothered by or have to avoid going Outside because of <b>weather or air pollution</b> ?	1	2	3	4	5	6	7

How **limited** have you been **during the last 2 weeks** doing these activities **as a result of your ASTHMA?**

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited
<b>12. Strenuous activities</b> (such as hurrying, exercising, running up stairs, sports)	1	2	3	4	5	6	7
<b>13. Moderate activities</b> (such as walking, gardening, housework, shopping, climbing stairs)	1	2	3	4	5	6	7
<b>14. Social activities</b> (such as talking, playing with pets/children, visiting friends/relatives)	1	2	3	4	5	6	7
<b>15. Work/school-related activities*</b> (tasks you have to do at work/school) <i>*If you are not employed or self-employed, these should be tasks you have to do most days.</i>	1	2	3	4	5	6	7

## ASTHMA CONTROL QUESTIONNAIRE ©

ELEVATE STUDY No \_\_\_\_\_

PT. INITIALS: \_\_\_\_\_ DATE: \_\_\_\_/\_\_\_\_/\_\_\_\_ VISIT: \_\_\_\_

### ALL QUESTIONS MUST BE ANSWERED

Circle the number of the response that best describes how you have been during the past 2 weeks.

- |   |                                     |
|---|-------------------------------------|
| 1. On average, during the past week, how often were you <b>woken by your asthma</b> during the night?             | 0 Never                             |
|   | 1 Hardly ever                       |
|   | 2 A few times                       |
|   | 3 Several times                     |
|   | 4 Many times                        |
|   | 5 A great many times                |
|   | 6 Unable to sleep because of asthma |
| 2. On average, during the past week, how <b>bad were your asthma symptoms when you woke up</b> in the morning?    | 0 No symptoms                       |
|   | 1 Very mild symptoms                |
|   | 2 Mild symptoms                     |
|   | 3 Moderate symptoms                 |
|   | 4 Quite severe symptoms             |
|   | 5 Severe symptoms                   |
|   | 6 Very severe symptoms              |
| 3. In general, during the past week, how <b>limited were you in your daily activities</b> because of your asthma? | 0 Not limited at all                |
|   | 1 Very slightly limited             |
|   | 2 Slightly limited                  |
|   | 3 Moderately limited                |
|   | 4 Very limited                      |
|   | 5 Extremely limited                 |
|   | 6 Totally limited                   |

4. In general, during the past week, how much **shortness of breath** did you experience because of your asthma?

- 0 None
- 1 A very little
- 2 A little
- 3 A moderate amount
- 4 Quite a lot
- 5 A great deal
- 6 A very great deal

5. In general, during the past week, how much of the time did you **wheeze**?

- 0 Not at all
- 1 Hardly any of the time
- 2 A little of the time
- 3 A moderate amount of the time
- 4 A lot of the time
- 5 Most of the time
- 6 All the time

6. On average, during the past week, how many **puffs/inhalations of short-acting bronchodilator** (eg. Ventolin/ Bricanyl) have you used each day?

- 0 None
- 1 1 - 2 puffs most days
- 2 3 - 4 puffs most days
- 3 5 - 8 puffs most days
- 4 9 - 12 puffs most days
- 5 13 - 16 puffs most days
- 6 More than 16 puffs most days

### C.3. Medication Adherence Report Scale (MARS) Questionnaire

Permission to use provided by Rob Horne

## QUESTIONS ABOUT USING YOUR PREVENTER INHALER

- Most people find a way of using their medicines which suits them
- We are interested in what method best suits you
- Here are some ways in which people have said that they use their preventer treatment

***For each statement , please tick the box that best applies to you***

	<b>Your own way of using your preventer treatment</b>	<b>Always</b>	<b>Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>
M1	I only use it when I need it					
M2	I only use it when I feel breathless					
M3	I decide to miss out a dose					
M4	I try to avoid using it					
M5	I forget to take it					
M6	I alter the dose					
M7	I stop taking it for a while					
M8	I use it as a reserve, if my other treatment doesn't work					
M9	I use it before doing something which might make me breathless					
M10	I take less than instructed					

## C.4. Patient Information Sheet and Consent Form

### STEP 2 PATIENT INFORMATION SHEET

<b><u>Study Title:</u></b>	Clinical and health economic evaluation of leukotriene receptor antagonists	
<b><u>Patient Name:</u></b>	<b><u>Information Sheet edition &amp; date:</u></b>	Version 4 4/9/2003
<b><u>Doctor(s) Directing Research:</u></b>	<b><u>Doctor(s) Telephone Number:</u></b>	
<b><u>Practice Asthma Nurse</u></b>	<b><u>Nurse Telephone Number</u></b>	

***PLEASE READ THE FOLLOWING INFORMATION CAREFULLY.***

#### **What would I have to do?**

You are being invited to take part in a clinical research study to help answer how effective different treatments are in helping people like yourself with asthma.

People with asthma have inflamed air passages, which cause symptoms such as cough, wheeze and shortness of breath. The inflammation is often treated with inhalers containing a medicine called a corticosteroid ('steroid' for short). More recently, however, tablets which treat the inflammation in a different way have been introduced and this study aims to see which of these treatments is more effective. Both of these treatments are currently available and are used in the treatment of asthma in the UK. This study will involve about 700 patients around the UK.

You currently do not receive regular preventative treatment for your asthma but your doctor or asthma nurse now feel that it might be helpful to consider commencing regular preventative therapy.

If you agree to take part in this study you will need to visit your doctor or practice asthma nurse for 5 study visits over a 2 year period which will be similar to your normal asthma care. You and your doctor or nurse may arrange extra attendances, as you or they feel clinically appropriate.

For 2 weeks before each of the five study visits you will be asked to complete a diary regarding your asthma symptoms, the number of times you need and use your blue reliever inhaler and your peak flow reading morning and night.

At each study visit your doctor or nurse will ask you to complete two questionnaires that measure the impact of asthma on your quality of life. If you have trouble with eczema, dermatitis, rhinitis (nasal blockage, itch or drip) or hay fever you may be asked to complete questionnaires regarding how badly these are affecting you.

If you agree to participate in the study you will complete the diary card mentioned above for two weeks to see whether your asthma is giving sufficient problems to justify the additional treatment. If it is you will be randomly allocated, (by chance, like with the toss of a coin), to one of the two treatment choices mentioned above either the steroid inhaler or tablet therapy. Your doctor or nurse cannot alter this allocation.

If you have been allocated to the tablet treatment your doctor will prescribe one of the two different tablets available montelukast (Singulair™) or zafirlukast (Accolate™).

If you have been allocated to the steroid inhaler treatment your doctor will prescribe one of the range of different preparations available beclomethasone (e.g. Becotide™, Becloforte™, Beclazone™ and QVAR™), fluticasone (Flixotide™) or budesonide (Pulmicort™) are some of the most common.

You will continue these treatments for a two month trial period. Depending on your response to this addition to your treatment, your doctor or asthma nurse may then modify your treatment to try and achieve the best possible control of your asthma.

Your doctor or asthma nurse will issue you with a self-management plan outlining what you should do in the event of a worsening of your asthma, development of a cold etc.

You will still be allowed to take your regular reliever medication should you need it but if you do you should make a note of it on your diary card for the periods you are completing this. If you require any other asthma medication you should discuss this with your doctor or asthma nurse first, if possible, unless it is part of your self-management plan.

### **Optional in depth interviews:**

**You may also be asked to take part in some more in depth interviews about your asthma and your medication over the course of the study. At your preference, these interviews may be conducted at intervals of 3 to 6 months, in your residence or at your GP practice. They will be between ½ and 1 hour in length. You may agree or decline to have these interviews without it influencing your participation in the remainder of the study or your care. All interviews will be recorded on audiotape but will remain confidential. At no point will your name be associated with recordings of the interview and the tapes will be destroyed as soon as the researcher has finished examining what you have said.**

### **Who should not enter the study?**

Your doctor has a full list of the types of patients who can take part in this study for example you must be aged over 16 and the results of your lung function tests must meet set criteria. There may also be other reasons why you cannot participate, in particular you should not take part if you are or intend to become pregnant during the study duration or are currently breast feeding. You can discuss this in more detail with your doctor or asthma nurse.

### **What will be the benefits and drawbacks?**

It is possible that no therapeutic or other direct health benefits may result during or following completion of this study, however, the information obtained about your condition during the course of the study may be helpful to your doctor in planning your care. In particular, it is uncertain which of the two treatment options may be most helpful to you. However, studies to date suggest that either of the treatment options give some benefit to the majority of asthma sufferers, in particular improvement in quality of life, reduced asthma symptoms and attacks. In addition, you may help other patients with asthma, as the information we get from this study may be useful scientifically.

All medicines may cause some side effects. For those allocated to treatment with a tablet more common possible side effects that have been noted from some people include headache, stomach pain, dizziness, fatigue, diarrhoea, fever, heartburn, toothache, nasal congestion, trauma, cough, mild changes in some blood tests and skin reactions (rash/swelling). Your doctor can tell you more about these. There may also be side effects of the treatment that are not presently known. It is not known whether the tablets may cause problems for a developing baby. For this reason we will not include patients who



may become pregnant over the next two years. For this reason, if during the study you become unintentionally pregnant you must consult your doctor as soon as possible.

For those allocated to the steroid inhaler possible side effects that have been noted in people include hoarseness, thrush in the mouth or throat, fluid retention or rash. There is also the extremely rare possibility of paradoxical bronchospasm (an unexpected wheezing attack – please ask your doctor for more information).

It is unlikely that you will have a serious side effect or injury resulting directly from this study particularly as all the treatments used are currently licensed for the treatment of asthma. If you do you should discuss this with your doctor immediately. Because the research is sponsored by the NHS there is no provision to offer advance indemnity to participants. A person suffering injury as a result of having taken part in research will need to pursue a claim for negligence through litigation or may be offered an ex gratia payment. Each case will be considered on its merits.

Should any new information become available about any medication included in the study during your participation which may alter your decision to enter or continue you will be informed by your study doctor.

If you agree to participate in the study, unless required by law, only government drug regulatory authorities and your doctor or asthma nurse will have access to your medical notes. Under direction of your doctor, authorised representatives of the University of East Anglia and the Independent Ethics Committee can see the parts of the notes relevant to the clinical study. Such data may also be seen by government drug regulatory authorities. This information will be treated in the strictest confidence. All information about you will be anonymised, your name will not be shown on any forms sent to the University of East Anglia or on any reports or publications resulting from the study. The only exception is that the University of East Anglia will keep a separate record of your name and address to send you the study questionnaires.

The study has been reviewed and approved by an independent panel which included doctors, nurses and non-medical people.

You should be aware that your study doctor will be paid by the NHS for the additional workload involved in his/her participation in this study and may not mean you carry on the treatment given to you during the study.

### **What happens at the end of the study?**

Your doctor or asthma nurse will decide, with you, on the best future management of your asthma - this may involve a change in medication.

### **Can I refuse to take part in the study?**

Taking part in this study is entirely voluntary. If you prefer, you can decide not to take part without having to give any reason and your current asthma treatment will continue. If you do decide to take part, you can change your mind later and withdraw. Declining to take part will not affect your future medical treatment in any way.

Your doctor may have to withdraw you from the study if it is thought unsafe or inappropriate for you to continue or for administrative reasons. Your doctor may also withdraw you from the study if you find it difficult to comply with the requirements of the study. Again, your future medical treatment would not be affected.

### **Who should I contact?**

Your doctor and/or asthma nurse should have answered all of your questions. If you have additional questions during the course of this study about the research or your rights as a

research patient, you may address them to the doctor(s) or asthma nurse mentioned on the first page of this information sheet. Please contact one of these doctors in the event of any of the following occurring:

- (a) if you suffer an illness
- (b) if you feel different in any way
- (c) if you are admitted to hospital for any reason
- (d) if you are seen at casualty ( accident /emergency department) for any reason
- (e) you feel that your asthma is worsening between visits
- (f) if you are seen by a doctor who is not your normal one, please let him / her know that you are in this study.
- (g) if you become pregnant during the study.

***Thank you for taking the time to read this leaflet, if you have any questions please discuss them further with your Doctor or asthma nurse who will be happy to answer them.***

**DECLARATION OF CONSENT**

**ELEVATE - Effectiveness of Leukotriene receptor antagonists in the  
EValuation of Asthma Therapies and for health Economics**

Investigator'/GP's:..... Asthma Nurse: .....

Address.....

Telephone No: .....

**(The patient should complete the whole of this sheet himself/herself)**

Delete as Applicable

- |          |  |        |
|----------|--|--------|
| 1.       | Have you read and received a copy of the Patient Information Sheet dated: <b>4.9.2003</b>  | YES/NO |
| 2.       | Have you had an opportunity to ask questions and discuss this study?   | YES/NO |
| 3.       | Have you received satisfactory answers to all of your questions?   | YES/NO |
| 4.       | Have you received enough information about the study?  | YES/NO |
| 5.       | Who have you discussed the study with? Dr/Mr/Ms.....   |        |
| 6.       | Do you understand that you are free to withdraw from the study:  |        |
|          | - at any time?   | YES/NO |
|          | - without having to give a reason?   | YES/NO |
|          | - and without affecting your future medical care?  | YES/NO |
| 7.       | Do you understand you should report possible side effects, changes to medical treatment and other health changes.  | YES/NO |
| 8.       | Do you understand and agree to authorised representatives of either the University of East Anglia, Independent Ethics Committee, or government regulatory authorities reviewing your medical records to check clinical information relevant to the study, on the understanding that your confidentiality will be respected and you will not be identified in any report? | YES/NO |
| 9.       | I understand and agree that information about me arising from my participation in this study will be processed by the University of East Anglia. This information may include my initials and date of birth but not my full name or address. The University of East Anglia will:   |        |
|          | - Analyse my clinical data during and after the trial, to assess the treatments involved in the study and to produce reports;  | YES/NO |
|          | - Such data may be seen by government regulatory authorities.  | YES/NO |
| 10.      | Do you agree to take part in this study?   | YES/NO |
| Optional |  |        |
| 11.      | Do you agree to be interviewed about your asthma and your asthma medications?  | YES/NO |

<b>SUBJECT</b>	<b>Study ID number:</b> _____
.....	.....
<i>Name of Subject (Please Print)</i>	<i>Signature of Subject</i>
<b>PARENT OR GUARDIAN (FOR SUBJECTS AGED 16 OR 17 IN ENGLAND AND WALES)</b>	
This is in addition to consent from the subject themselves	
.....	.....
<i>Name of Parent or Guardian (Please Print)</i>	<i>Signature of Parent or Guardian</i>
<b>CONSENT OBTAINED BY:</b>	
.....	.....
<i>Name (Please Print)</i>	<i>Signature</i>
<b>IF CONSENT NOT OBTAINED BY A PHYSICIAN, THE PHYSICIAN AVAILABLE TO ANSWER PATIENT'S/SUBJECT'S QUESTIONS MUST SIGN BELOW:</b>	
.....	.....
<i>Name (Please Print)</i>	<i>Signature</i>

## Appendix D

### Other work undertaken not included in main text

#### D.1. Analytical Process to Identify Participant's Accounting Styles

The extracts included in this appendix represent the early analytical attempt to identify participant's accounting styles which were then used to build a sample of participants to interview a second time. To identify each person's style the following procedure was followed. First, the recording of interviews were listened to and the author wrote a summary of the content of the interview to characterise how the individual justified their medicine taking. Second, these characterisations were imported into Nvivo software and then coded for rhetorical devices the participant's appeared to have deployed and the effects that this talk appeared to perform. Third, coded devices were grouped into categories which were designated an "interpretative repertoire". Further devices were then classified within existing interpretative repertoires or new repertoires were created. Definitions of repertoires were refined as necessary. Finally, the summaries of interviews were then re-read with devices, effects and interpretative repertoires highlighted. This re-reading enabled the author to construct the individual's particular accounting style. Having identified participant's accounting styles, participants were then compared to see whether groups of accounting styles could be identified and which would form a basis for a second round of interviews.

#### Extracts from Characterisations of Interviews

##### *Extract 1 – Characterisation of face-to-face interview with participant no. 650493.*

*The analytical process for this participant can be traced in this appendix from this characterisation to the identification of rhetorical devices (D.2.) to the mapping of this 650493's accounting style to other participants (D.3.).*

Participant no. 650493: early in tape discusses how uses prophylactic med in relation to circumstances. Self-regulatory/monitoring repertoire?

Continues this idea with contrast between what he would do if weren't in trial compared with being in it. In trial: will continue to take "for purposes of trial"; if weren't in trial would stop ICS because "I feel perfectly alright". "Fairly structured" "ongoing assessment". Further supported with descriptions of taking preventive treatment before going on holiday.

Salbutamol a "lifesaver". "As long as I've got salbutamol I'm happy". "once you wheeze...you get anxious"

When asked about the need for long-term management and ideas of risk of severity and that he referred to himself as having "had a good innings" he hinted that he felt vulnerable, but seemed to hesitate over this and was quite vague, perhaps was uncomfortable with my line of questioning.

Expresses (as an ex-GP) "dissatisfaction" (both himself and within medical profession) of state intervention into how to treat asthma. Used this to justify that "don't mind too much if I deviate a bit from what I'm told". Agreed in the principle of guidelines. "Docs are now civil servants. 'Doctors' are a sideline". Interesting contrast with own practice as a GP that when I ask "did you tell your pts to take the med 2 times twice a day" he replied "Oh yes, you gave them the official line, certainly" and mentioned how that was appropriate for some people but not others who have a "more adventurous spirit". Other extreme "downright casual" "cavalier"

**Accounting Style:** Self-regulatory, supported by criticism of government involvement in chronic disease management which suggests that adherence is inappropriate for some people, who have a more 'adventurous spirit'. This categorisation positions those who adhere regularly as more passive accepters of medicine.

***Extract 2- Characterisation of face-to-face interview with participant no. 670287***

Participant no. 670287 – interview at home.

1<sup>st</sup> statement: "I'm only really a mild case so it ((completing MARS questionnaire)) was quite easy because the asthma don't actually interfere much with my life anyway"; "I take less than instructed, probably that's the area that I had to admit to"

Asked about diagnosis: "I suppose a lot of it is putting a label on, what as a child, symptoms we didn't know what they were". Lived on a farm, lots of animals, dust, mother had an old mattress in the attic, as kids used to go bouncing on it, always came back with puffy eyes, wheezing "but we didn't put a label on it, it was just a thing that you did if you did that". Links hayfever to wheeziness, "obviously", "suffered from hayfever but didn't put a label on it". Says that hayfever/asthma is in the family as father had it "allergic to (green wood?) on apple trees". "Dad had it, we had it and it wasn't an issue because we knew what triggered it off and we avoided it". At school avoided running around by going in goal at football, "but again we weren't putting a label on it, it was accepted, we were brought up with it, wasn't a problem".

As if a diagnosis creates a problem. Medicine imposes rules to follow which creates the problem hence statements such as "I had to admit" to taking less than instructed. The embodied experience is almost irrelevant, rather it is society's response to the experience which creates difficulties.

By constructing his asthma in this way he builds picture of himself as engaged with the condition, takes responsible steps to avoid triggers which forms the basis for any decisions not to take medicines as instructed.

"obviously grain dust and animals did bring me out in a rash, but quite often wheeziness". Trivialises by using opening term obviously. Then discusses having scratch test at GPs which identified cow hairs, cat hairs and house dust as triggers. Brings in medical proof to verify his own interpretation.

Daughters have got the same kind of symptoms, "the family trait as it were". Again objectifies the cause. Youngest daughter is "more of a pollen person really". Pathological varieties reinforce the functional power of the medical repertoire.

Then tells story of 10yrs ago when had chesty cough, which tends to go a bit wheezy, "one night took a turn for the worse" took some of daughter's ventolin, only 1 puff to see if get some relief "as didn't want to overdo it". Eased it for 15mins. Remembers "standing outside in cold night air trying to get air and breathe, actually was getting quite worried at that stage". Next day rang docs and "they actually came out and immediately taken to A&E", got nebuliser and was in hospital for 2 days, "then the

label was put on it ‘*you’ve got asthma*’ and from there on all the medication then kicked in, and you know I’ve been in control of it and I’ve never had a repeat of that occurrence. The only, recently what was happened with the brown...I was told to take it all the while, but I dropped off then missed a dose, in then end, recently just been taking it if there was a chesty cold coming, been around people with colds, a quick dose and that helped me through it, I’m afraid I dropped it off after that. Just sort of a life history of the disease and its impact”.

This ends the opening narrative. Builds self as responsible person (which was supported by medical evidence) before the onset of the asthma attack which described in detail adds drama to the day of diagnosis. He seems to providing proof of the condition but also that he acted responsibly in that situation (rubberstamped by admission to A&E) which predicates the subsequent talk on the use of brown inhaler. The style then is a combination of medical and responsible repertoires which interplay to form justification of non-adherence. His closing statement is interesting as asthma is constructed as an independent entity which has impacted upon him, rather than referring to it in the possessive sense.

Slight contrast to Cornwell’s legitimacy exonerates the need to justify. Here there is a more complex interplay between providing proof to prepare the grounds to justify and manage potential accusations of irresponsibility.

Asked about personal significance of having label of asthma. “It doesn’t bother me” In the family has always been eczema, hayfever and asthma. I just happened to get all 3. “It is a family weakness”.

Reports life changed after diagnosis, so has a before and after story. Before “it wasn’t interfering with your life to that extent” “perhaps I was treating too lightly, until that attack, then realised going to the hospital in the ambulance, the kidology stops now because actually this is pretty serious”. So this changes the interpretation of the earlier talk with this before and after story. Now he takes seriously whereas before he didn’t. Told as children ‘you would never die of asthma, but of course is serious if not under control’. So is using a more compliant repertoire in the after story based on ‘new knowledge and experience’. This would seem to provide an explanation to the before story which removes personal blame. In Cornwell’s framework the absence of proof

locates the breathing problems in the before story as a 'health problem that is not an illness' which therefore requires that personal blame for the problem be dealt with. He achieves this with detailed description of his activities as a child and the triggers, a shared awareness in the family of this, but justifies not taking as seriously as he should do (and therefore not taking meds) because he lacked the correct information. "that was the time the significance of the problem was realised, but before then it was inconvenient". The story is the marker of this change. The use of detail adds drama then to mark this as the point where his response to the embodied experience shifted.

Goes on to use self-regulatory repertoire. "It's about knowing where the problem is, then avoiding it, if you can't avoid it, do something about limiting the effects it can have".

Described salbutamol as "your friend" who is always with him wherever he is. Uses brown when gets a cold but doesn't think it does much. "Obviously is a preventer so you can't tell if it has done any good or not" Thinks he has been using it incorrectly, because "you need to use it on a regular basis, not just in an emergency" "and I've been neglecting that should be using it all the time on a regular basis". Says he has been shown how to use it, and knows how to use it. Thinks explanation of the brown came from the GP. Describes in detail what was told about a nebuliser and that you can take a lot of salbutamol if need to which was "a comfort" because it is "so so effective with me" he only needs one puff. "and if it is so effective one wonders what the brown one, what use is that brown one". Describes how was on other med for his eyes and was warned about overusing it so he thought "do I need to be hooked on all this stuff, is there anything I could drop off, obviously I suppose the Beconase was one of them" ((think he means brown inhaler here)). Uses addiction repertoire to justify not taking brown, overuse is akin to being an addict, "hooked".

For him, salbutamol provided the answer. He could control his asthma, acting responsibly by complying with the demands of asthma management, whilst avoiding becoming "hooked" on drugs. The brown inhaler is constructed as an option which he could "drop off", the blue acting as a better alternative. This possibly has links with Cornwell's private worlds. How the medicalization process is assimilated (in a bottom-up fashion) into sub-cultures. Whilst salbutamol is assimilated comfortably "is a



comfort” the brown inhaler is not easily accommodated, as it falls within a “drug-users” discursive framework.

Hasn't been back to the surgery to discuss, vaguely mentions that a GP may have wanted to manage differently but “stress it is not a debilitating problem in as far as my work is concerned”. Says because he is in a managerial position he can get others to do tasks which might affect his asthma, which they understand.

When asked to use brown inhaler for the study he said “Fine. If it is part of the study” Talked about trying to take “religiously”. Discussed not knowing long-term effects of taking the preventative are, “doesn't seem to have any side-effects, effects your voice, suppose you get to adapt to that, accept it”. Largely uncritical of specific medicines but has particular praise for blue inhaler, “it is so good, you forget the reason you took it”. Mentions one of the personal orientated targets for the study was to reduce dependency on medication, doesn't talk much more about this but earlier talk is informative here. 2<sup>nd</sup> target was to be able to do more activity at work, but was at pains to play this down, “asthma is a nuisance” “not a serious issue” “not something I worry about at all”. Refers back to the asthma attack as the “crisis” that “frightened me, probably did me good, made me treat it with respect”.

I ask about whether he thinks practice view his asthma differently to him and he discusses the idea of respect. That he is not doing what they told him to do so I'm not treating them with respect. “If I gave advice to somebody who then blatantly ignored it, I tend not to actually treat them with the same respect or care, than somebody who was actually trying to do as they were told”.

Avoids direct criticism of practice by saying they are following “standard procedure”. When I ask what he thinks is going on in terms of his and their goals he says that he hasn't analysed that deeply really. Hasn't engaged with the idea of not following their advice. Could explore ideas of work and respect and how linked to health and illness for him.

Asked about what would do beyond study “if it proves to be effective, the considered opinion of the experts that it is the way it should be controlled rather than the curative, I will do as I'm advised, by people who I would trust to advise me correctly rather than

any self-opinionated thoughts that I knew better. I've got every faith in the medical practice. If the study is 6 or 7 years, spend the time with consultants and specialists and they advise you and you don't do it, then it is to your discredit I think." If proved preventive med is responsible for reducing symptoms then "so be it".

*Post-interview comments:*

21/12/04: participants number 670287 – comments made when listening to tape for characterisation on 28/7/06

Remember feeling irritated with his attempt to adopt some kind of powerful position in the interview. Didn't want to "brag" about being a manager. Challenged me when I asked how long he had been taking the brown inhaler "you should know". Not sure why I feel this happened, maybe because of the potentially accusatory nature of the interview, with a potential power imbalance between questioner and responder. I also mentioned it was a student project so perhaps that gave him a slight feeling of authority.

***Accounting Style:*** Uses effect of labelling symptoms with "asthma" as the key rhetorical tool in managing accountability. Before and after story justifies his actions through the use of this labelling device and the traumatic event associated with the diagnosis. Reinforced with "self as expert" devices, utilising medical evidence to authenticate his own interpretations. Non-adherence constructed as minor deviation from position of control. Self-regulatory repertoire used when arguing how in control of asthma now. This disappears when discussing reasons for not taking ICS in favour of an 'overuse' and addiction repertoire, but defers to medical expertise and blames self for not following their advice, so upholds the medical agenda of compliance as the ideal. Asthma constructed as not an issue as seems to represent threat to his lifeworld.

### **Extracts from Analysis of Interview Summaries for Rhetorical Devices and Effects**

The following is a list of devices and effects used to generate identification of the self-regulatory repertoire. These were preliminary categorisations that were used to build a sample for a second round of interviews. Note that the attached comments, the "Internal Dbs", on devices and effects may refer to a larger piece of text than that coded as

performing a specific effect. It is useful to include however as it helps place the coded text in a broader sequence of the interaction.

The following eight effects were identified as making up a self-regulatory repertoire:

- 1 . Acceptance of utility of meds
- 2 . Asthma as 'not an issue'
- 3 . Compliance is passive
- 4 . In control
- 5 . Independent, engaged, not compliant
- 6 . Medicine taking is an addiction
- 7 . Self-aware
- 8 . Undermines solidity of knowledge

The following extracts are sections of different interviews that were coded in NVivo with Effect 3, “compliance is passive”, (paragraph numbers refer to NVivo not transcript).

***Compliance is passive – Extract 1, participant no. 650493***

Passage 1 of 8 Section 0, Para 14, 160 chars.

*14: “Oh yes, you gave them the official line, certainly” and mentioned how that was appropriate for some people but not others who have a “more adventurous spirit”. [3]*

[3] Internal DB. Device and effect: uses consensus with medical colleagues to undermine authority of asthma guidelines dictated to by 'state intervention'. This justifies deviating "from what I'm told" but then uses the other extreme to position self between two extreme points. "more adventurous" implies adherence has an obedient connotation, whereas the other extreme is more reckless "downright casual", "cavalier"

***Compliance is passive – Extract 2, participant no. 121350***

Passage 2 of 8 Section 0, Para 25, 78 chars.

*25: “pumped into me all the time. Everyday.” “More likely to get bruised and cut[5]”*

[5] Internal DB. Device and effect: passive metaphor, body as receptacle. Effect is to position those who take inhaled steroids regularly as passive objects which positions

herself as an active person. Use of claim of physical outcome gives position scientific credibility which adds authority to her position. Clear contradiction in the use of this device as it is medical knowledge which is being challenged by adopting this position.

***Compliance is passive – Extract 3, participant no. 351823***

Passage 4 of 8 Section 0, Para 220, 437 chars.

220: *Used to work on a respiratory ward as a nurse, knew how to use inhalers as has given that advice to other people. “done that, on ‘drug rounds’ ((laughter on the term drug rounds)) for a long time, I recall very clearly thinking ‘I don’t know how you do that’, you know I don’t think I could, I don’t enjoy using at all, it really does make me gag... if it’s bad enough you do.. did already have ideas of not liking that mode of something”[36].*

[36] Internal DB. Device and effect: story of when worked on respiratory ward on 'drug rounds' provides a relational positioning between herself and the patients on the ward. Herself as someone not able to take meds as they "make me gag", whereas she about the patients thought "I don't know how you do that". Her use of the term 'drug rounds' and associated laughter suggests her discomfort with this term because the passive position it places patients in. The story perhaps carries the message that taking medication is for the sick.

***Compliance is passive – Extract 4, participant no. 121350***

Passage 3 of 8 Section 0, Para 39, 75 chars.

39: *Grandparents rather than lots of inhalers “rather than just give up on it”[10].*

[10] Internal DB. Device and effect: Grandparents positioned as 'giving up on it' for taking lots of meds unquestionably. This relational positioning identifies herself as actively engaged with the impact medications have on her body.

The following extracts are sections of different interviews that were coded in NVivo with Effect 5, “Independent, engaged, not compliant”

***Independent, engaged, not compliant - Extract 1, participant no. 650493***

Passage 1 of 4 Section 0, Para 14, 657 chars.

14: Expresses (as an ex-GP) “dissatisfaction” (both himself and within medical profession) of state intervention into how to treat asthma. Used this to justify that “don’t mind too much if I deviate a bit from what I’m told”. Agreed in the principle of guidelines. “Docs are now civil servants. Doctors’ are a sideline”. Interesting contrast with own practice as a GP that when I ask “did you tell your pts to take the med 2 times twice a day” he replied “Oh yes, you gave them the official line, certainly” and mentioned how that was appropriate for some people but not others who have a “more adventurous spirit”. Other extreme “downright casual” “cavalier[3]”

[3] Internal DB: Devices and Effects: Uses consensus with medical colleagues to undermine authority of asthma guidelines dictated to by “state intervention”. This justifies deviating "from what I'm told" but then uses the other extreme to position self between two extreme points. "more adventurous" implies adherence has an obedient connotation, whereas the other extreme is more reckless "downright casual", "cavalier"

***Independent, engaged, not compliant – Extract 2, participant no. 121350***

Passage 2 of 4 Section 0, Para 21, 262 chars.

21: Learnt from Grandparents (who both have asthma) that smoking was bad. “you couldn’t find someone more against smoking than me”. They have a lot of inhalers because they smoke, “I only have 1”. “I don’t want to be on that much medication, even when I’m their age[4]”

[4] Internal DB. Devices and effects: Uses story of Grandparents to position self as not at the mercy of medications and asthma and is engaged with her health. Having a lot of medication seen as a result of smoking. Assertion that "you couldn't find someone more against smoking than me" strengthens her position.

***Independent, engaged, not compliant – Extract 3, participant no. 121350***

Passage 3 of 4 Section 0, Para 25, 78 chars.

25: “pumped into me all the time. Everyday.” “More likely to get bruised and cut[5]”

[5] Internal DB. Device and effect: passive metaphor, body as receptacle. Effect is to position those who take inhaled steroids regularly as passive objects which positions herself as an active person. Use of claim of physical outcome gives position scientific credibility which adds authority to her position. Clear contradiction in the use of this device as it is medical knowledge which is being challenged by adopting this position.

*Independent, engaged, not compliant – Extract 4, participant no. 121350*

Passage 4 of 4 Section 0, Para 39, 75 chars.

39: Grandparents rather than lots of inhalers “rather than just give up on it”[10].

[10] Internal DB: Device and effect: Grandparents positioned as 'giving up on it' for taking lots of meds unquestionably. This relational positioning identifies herself as actively engaged with the impact medications have on her body.

**Mapping Accounting Styles**

On the following page is an extract from the final step in building a sample of participants that could be interviewed a second time. Each person’s accounting style is summarised in the first column. The second column indicates the key theme to emerge from that style that links them with other participants. The bold 1s mark the style documented for that person and tally with their study ID on the top row. The red 1s mark where else a person's style might be categorised and so indicate how many people might be grouped into a particular style. Participant 650493 can be used as a starting point.

(Original in colour)

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1	SID HO	The bold 1s mark the style documented for that person and tally with their study ID on the top row. The red 1s mark where else a person's style might be categorised and so indicate how many people might be grouped into a particular style.	Key theme in accounting for non-adherence	550/84	12/12/21	530/191	12/10/28	500/67	3/09/15	600/308	650/83	12/13/50	6/02/89	650/05	2408/76	28/9/06	6/06/19	6/02/17	28/12/84	14/16/93	5/11/41	6/02/85	6/02/83	33/18/23	1/10/28	6	43/18	4/09/04					
2		Accounting Style																															Sum for
11	650493	Self-regulatory, supported by criticism of government involvement in chronic disease management which suggests that adherence is inappropriate for some people, who have a more 'adventurous spirit'. This categorisation positions those who adhere regularly as more passive accepters of medicine.	Compliance as passive. Positions self as engaged and responsible and in control							1	1																						
12	650263	Responses were brief and gave impression of being disengaged with illness. Was concerned that through own desire to uncover some depth my questions were suggestive of 'something to hide' or 'you need to take your asthma more seriously'.	Unwilling, unable, or nothing to justify. Use of minimisation repertoire	1	1	1		1			1	1	1					1															
13	121350	self-regulator. not an over-user unlike her Grandparents who are 'giving up on it'.  Little justification (Don't need to take) despite conceding might benefit from regular med. Simplistic style and disengaged with illness. Appears on the surface to be little	Compliance as passive. Positions self as engaged and responsible and in control  Unwilling, unable, or nothing to									1	1																				

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## **D.2. Ethical issues regarding informed consent with individual participants.**

Used as a starting point: Ramcharan & Cutliffe (2001) “Judging the ethics of qualitative research: considering the ‘ethics as process’ model”.

### ***Context of research interviews***

Theoretical rationale of study implicitly hypothesises that participants’ are perhaps “disengaged” in some way from their illness. There is a structural relationship between myself and participant, “researcher from UEA, asthma study taking place at GP surgery – patient”.

### ***Ethical/Research issues***

- 1 . Fully informed consent of research aims. Patients are currently consented for interviews about their views of asthma and medications. Whilst this is a broad area I feel there is a need to inform aim of research is about morality/identity and risk tensions, (in some form). This would seem desirable both for form of interview questions and for the patient’s awareness of research aims.
- 2 . Objective to explore in-depth aspects of morality-risk-adherence relationship versus individual’s right to remain disengaged from their asthma. Danger of causing tension between myself and interviewee, their doctor/nurse and/or perpetuating how patient identifies with their asthma through the research relationship.
- 3 . Informing of aims. Need to strike balance between informed consent and producing contrived data. It is important not to be too focused as other important insights will be missed and my own preconceived ideas will be in danger of becoming self-fulfilling prophecies in the data.

### ***Proposal***

- Application for ethical approval of new information sheet and consent form is not necessarily the most ethical approach. To introduce the research aims at outset of interview is likely to frighten participants and undermine the data.



- Secure verbally agreed informed consent with individual participants. Explain how the aims of the interviews have developed since I have become a postgraduate. Explain that it would also be useful to understand some of the social and personal issues which influence how people live with their asthma, and how asthma care might be provided differently. I would like to understand not only patient's views about their asthma and medication, but more specifically the reasons why the person has these views. Explain that understanding this may involve discussing how the patient views health and illness in general, lifestyle choices and the person's attitudes to life in general. Make explicit my independence from Elevate in these interviews and the participant's GP surgery. Re-emphasise anonymity and confidentiality.

### D.3. Reflections on focus group and role of moderator

It is clear from the audiotape of the focus group discussion that participants framed me as an expert on asthma until the end of the focus group discussion where it became a lot clearer:

P5: I thought that um I was expecting you to inform us of all the er

P2: yeah

P5: all the things we should and shouldn't be doing

P2: yeah

JM: what gave you that impression

Several: heh heh heh

P1: we thought you were an expert

JM: what do you think now?

P1: Not sure heh heh heh

(Data sharing focus group, page 36, line 48 to page 37, line 13).

This is despite stating both in the face to face interviews and at the beginning of the focus group that I have not been medically trained. There was it seemed a common perception that I was in a position to communicate to them the value of medications, their side-effects, how they compare to other medications and also objective definitions of asthma. This is not surprising given the initial context in which I met them for face to face interviews (a health researcher working on the main asthma RCT in which they are participating).

This shared perception was enhanced further in conversations prior to commencing the focus group. I was asked what sorts of patients were being studied in the asthma study. I do not have a note of the exact wording of this question but I evaluated this question in the following way before responding: this person is perhaps wondering if there is anything special about their invitation to the focus group today other than that I had interviewed them? Perhaps they are concerned that I/the main study considers their asthma to be more severe than they do?

I therefore responded by explaining the particular medications that they would need to be taking to be recruited and then unfortunately got too technical and explained that there are 5 asthma steps and they were being recruited at step 2. I did this to try and answer what I considered to be his concern without stating that his asthma was mild. It was then stated by either himself or somebody else present that they were at the milder end of the asthma spectrum.

I also provided them with a brief summary of the findings of the main study in response to a question I cannot specifically remember. These discussions only served to reinforce the idea that despite my protestations I was an expert on asthma and I can provide them with answers to specific clinical questions about asthma.

The questions are: How does this impression impact upon the data that I have collected? The whole point of the focus group was to provide data based on a different set of contextual conditions. This was achieved in terms of the time and location (beyond the end of the RCT and not in participants homes but neither an NHS or university venue); in terms of the interactional dynamics, (other people with asthma talking to each other around a table) and the type of activity (reviewing findings from the 1<sup>st</sup> set of interviews as opposed to direct questions about their own experience). Within those constraints participants were free to talk or not talk as they pleased rather than having to respond to particular questions about their own asthma.

Ethical Issues: Were participants under a false impression of the purpose of the focus group? It seems from the data that some or all participants thought that I was specifically interested in medications (and perhaps the pharmacology of medications) and did not grasp my primary interest in “attitudes” and “beliefs” until my disclosure that I had a background in psychology (page 37-39). The interviews that they had consented for were always presented as their views of asthma and medications, that is what was discussed and that is indeed what I am looking at. The purpose of the focus group was to provide some feedback on these opinions. This was clearly stated in inviting them to take part, both in the initial phone call and the confirmation letter. The materials presented were opinions about asthma and opinions about medications. What was not fully understood was my own position on these issues, but this whole research is highlighting these interactional issues that are prevalent in any research/clinical interaction and this is no different. As soon as I mentioned psychology it seemed that

they were more able to pigeon hole my agenda. An important point is that people in general are just not used to discussing their health and illness with anyone who is not a nurse or doctor and so it is difficult to move out of this expectation. It does not seem that their expectations of the task were not met, but rather their expectations of who I am and what information I might provide them were not met. Does this constitute a lack of consent? What may have been upsetting for people is that they became aware of how they might have talked differently “had they known”. But I can categorise myself in a number of ways and the one I have tried to use has been “student” which did not seem to make any difference. It is only when the asthma expert is stripped away that there is a space to fill. Secondly, after saying my background is in psychology are they now fully informed? What else do they not know about me? As we manage the distinction between the observer and the observed we make decisions about what information to provide, so as to not “bias” if you are a positivist, or to impose our own position on the data we decide where to draw the line, they can never know all about the researcher.

The emergence of their awareness that I was not an expert on asthma and my awareness of this came about through the process of the focus group, (my role as listener and not “filling the spaces” in conversation and their apparent discomfort with this, my inability to provide answers to their clinical questions) it did not come about through me repeatedly informing them that I was not an expert. In the face to face interviews the impression of an “asthma expert” was perhaps constructed, whereas here it was being deconstructed. This is perhaps evidence supporting that indeed we did have a different set of contextual conditions to the face to face interviews. What is interesting is how they managed this “new” information.

#### D.4. Analytical work Undertaken on Rhetoric and Discursive Space

##### *Reflections on transcript 670287 and Extract Nine, Chapter Four*

Participant 670287 (interview one, page 11, lines 35 to page 12, line 7)

M: =So I have it has been. But I stress it is not a debili(.)tating (.) problem insofar as my (.) y'know °my work is concerned or my you know my life is concerned. (.) Um (.) I don't play (.) football I do (.) occasionally bouts of strenuous work (1) um but its managed° and I'm very fortunate in that (.) you know I can choose (in the middle?) ((of something?)) what what I do (.) a- at work rather than (.) um (.) you know being in a managerial position I mean I don't wanna (1) y'know er (2) brag but you do have a little bit of flex(h)ib(h)ility um and if there's you know y'know there's somebody else available who will move the grain lorry up and you know I would do his job while he did while he did that (.) and if its unavoidable well I (.) I'll do you know put a mask on and move the lorry myself which is its not an issue as far as I'm concerned (1) you know the guy um (.) you know I can certainly ask somebody else can you just move down (.) while I take over from you= =Everybody knows that the reason I'm doing it I'm not frightened of work but they just (.) I can manage it in that way (.) um (.) so (.) I suppose you could say well actually you are changing your lifestyle but not to that degree.

Pollock (1993, p. 55) cites Freidson when she argues that patients with chronic illness in contrast to acute conditions are afforded “permanent legitimation” – on condition they make effort to “improve themselves” and are socially acceptable by minimizing the demands on others. These standards of acceptability, or ideologies of appropriate behaviour constrain or facilitate the number of positions afforded to people with illnesses. For example Pollock identifies a range of literature including her own where participants stress the importance of “attitude of mind” and “mind over matter” which are directly related to ideas about personal responsibility for, and control over, health and illness. She discusses how people diagnosed with multiple sclerosis are helped and

encouraged to adopt an “attitude of mind”, whereby a positive attitude is attributed to those people susceptible and experiencing positive health outcomes whilst a negative attitude attributed to those susceptible to and experiencing poor health outcomes.

In his account of how metaphor links domains of experience Radley (1993) discusses how spaces of action are available to people with illness between what is expected regarding their behaviour and what can be attained, between public morality and private fate, and how this space for agency regarding one’s behaviour is manifested in the discursive positions taken up by people when discussing their health.

The quality and size of this discursive space is what I am referring to as “affordance”. From a medical perspective, by minimising the impact of asthma this person in the above extract affords themselves the space to take up a wider range of positions than if their asthma was having a large impact on their life. However, what is being shown here is that whilst appropriate asthma management is being oriented to by the speaker within the demands of this specific interaction he is also managing the moral expectations of the different social networks in which he participates. The dilemmas that this creates do not merely orientate around being seen to be in control of one’s asthma but refer to much smaller “affordances” in the discursive positions of conscientious worker, a good manager and someone who has a health problem that is not an illness. The example of swapping duties at work as an acknowledged practice amongst his workforce demonstrates the boundaries of the behavioural space that the morality of the workplace affords him.

What this extract shows is that these different concerns are not discrete properties but are interwoven and at times managed simultaneously. Seen within all of these concerns, the medical agenda of adherence is only likely to play a small part. This creates dilemmas surrounding the need to appear both in control to a health researcher, (consider Horton-Salway’s (1998) concept of “double jeopardy” – where there is a catch 22 situation for the speaker). In adherence this might be between being categorised as irresponsible because the person has not taken preventive medication as prescribed and being categorised as irresponsible for over-use of medication, to be passive and dependent. Might be evident where someone is trying to straddle the moral frameworks of medicine and the lay world. See Horton-Salway (1998, p.179), who also cites Radley and Billig (1996).

This participant can be seen to manage differing perspectives on illness management and adherence according to the different interactional and ideological contexts, shifting position when the issue at stake shifts from his understanding, awareness and responsibility over his illness (pages 1-10 of full transcript for 670287, page 5 is a good example) to whether it has changed his lifestyle (again pages 1-12, but his biography in pages 1-3 and page 11 are good examples) to the appropriate behaviour for a research participant (page 13). In this last context, adherence is constructed more as “compliance” because he has “signed up”, and he would “hop around on one leg” if he was told to do so. There is no tension here with whether taking the prophylactic medication interferes with his life because it is judged within a context independent from whether he needs that medication in his everyday life and his position is therefore inoculated against the morality of those contexts. The clinical decision taken by a nurse, (supported by evidence regarding quality of life and level of asthma control obtained via study questionnaires) that he might benefit from taking regular preventive medication, (that represented an essential component in screening asthma patients for their eligibility to take part in the randomised controlled trial) is not seen to play a part at all here. The reason for this appears to be related to how he understands the main asthma study which seems to be as a new drug trial. His role within this study therefore is to act as a “tester” for these new treatments. This appears to construct a relationship whereby he is the willing, but arbitrary volunteer, and the medication is the object of analysis. He does not demonstrate an awareness that his participation in the study is (supposed to be) based on clinical reasons alone and that aside from the study this clinical decision would be that he needs to take the preventive medication everyday anyway. This hypothesis is supported on page 20, lines 36 to page 21, line 5) when asked about what he will do after the study he responds by referring to the specific efficacy of preventive medications as opposed to the “curative” and at other points where he refers to the study as a “survey” (page 13, lines 19, 40) and “scheme” (page 11, line 31).

670287, Interview 1, page 20, lines 30-50

JM: outside outside of that do you think what will happen at the end of the study will you stop taking it or

(1)

M: If its proved to be effective (.) and it is the considered opinion of the experts (1) that it is (.) um the way it should be controlled rather than the

curative (.) I will do as I'm advised (.) by people who (.) um (.) you know who (.) who I would trust to advise me correctly (.) rather than any (.) um (1) opinionated self opinionated thought thoughts that I thought I knew better. (3) I mean these I mean I have got every faith in in in you know in the medical practice I mean if if (1) ((rustling papers)) the study is 6 or 7 years and then spend the time and then you know with consultants and specialists (.) and they advise you to do something and you don't do it then I think basically its um (.) it's to your discredit I think (.)

What is of interest to the analysis here is the relationship between inequalities in possession of linguistic resources, affordances in discursive space, morality and therefore rhetoric. In this above example the adoption of a compliant position to the aims and objectives of medicine is a position on his future behaviour taken up well within what is expected from a medical perspective; he is respecting the authority of medicine, accepting of its science and willing to follow its commands. This compliant position can only be seen in a good light from a medical point of view. There is nothing to justify because the person is positioning his future, and as yet unaccountable behaviour, within the boundaries of medical expectation for someone with asthma. However, rather than simply stating his intention to take the medication if that is the advice, the speaker chooses to go further by providing a strong defence of medicine and discrediting a non-compliant position. With the absence of a competing set of moralities to which the speaker must orientate to he is afforded the space to take up as compliant as position as he wishes. Here we can see this with the way that he constructs a vivid contrast between the opinion of the experts, consultants and specialists which is "considered" and the "self-opinionated" thoughts of himself. Here this statement encapsulates the tension between the authority of science and the lifeworld but it is here where the lifeworld is subjugated as irrelevant, to be discredited.

In contrast to earlier sections of the interview (e.g. page 10), this person does not demonstrate the compliant position as having any conflict with other lifeworld moralities because the severity of his asthma is not at stake here. Through a combination of my own questioning and the person's understanding of the aims of the study his future behaviour is isolated from his own current clinical need to take prophylactic medication. He avoids having to enter into another rhetorical account of



how he manages his asthma and whether he should be taking regular preventive medication. It is the interactional elements of this particular sequence and his apparent lack of access to the linguistic resources of the study that explains the style of rhetoric that is deployed here and which contrasts so markedly with earlier discussions.

What is being proposed here is that, in addition to differing levels of discursive affordances according to differing social networks which is related to the amount and type of rhetorical work that takes place in a piece of discourse, rhetorical practice is regulated by the possession or absence of particular sets of linguistic resources, in this case what the randomised controlled trial is about, what it means, what is being tested. Here the participant is demonstrating that he does not possess an accurate understanding of the study and without the linguistic resources that go with that understanding his account and position on future plans after completion in the trial is inadequate when seen from the perspective of the researcher who does possess these resources and is deploying them to frame the question about future plans. What is not clear is whether the participant himself realises he does not have access to these resources, despite the “information” being provided.

## **D.5. Review of Health and Illness Literature to Assess the Relevance of Morality for talk about Health and Illness**

To understand the relevance of morality in the management of chronic illnesses today we need to examine why and how morality and health have been historically connected. In Britain the biblical link between sin and illness was activated by the Christian church in the 15<sup>th</sup> century (Thomas, 1997, pp. 15-34). Thomas cites the Elizabethan Puritan Perkins who said “Sickness comes ordinarily and usually of sinne” (Perkins 1608-1631, 1:497) to argue that when the godly man became ill they had to search themselves for what they had done wrong to bring such an affliction upon themselves or saw their illness as a test from God. This connection between purity and health on the one hand and immorality and illness is identified by Thomas across a range of health-related behaviours from the 15<sup>th</sup> to the 19<sup>th</sup> centuries - eating and drinking, cleanliness, smoking, sex and exercise. The reason for abstinence or moderation in these activities was commonly related not to any physical consequence but because of the moral connotations of that behaviour and Thomas cites Sir George Cheyne in 1725 to point this out,

The infinitely wise Author of Nature has so contrived things, that the most remarkable rules of preserving life and health are moral duties commanded to us, so true it is, that godliness has the promises of this life, as well as that to come” (Thomas, 1997, p. 24).

These connections between morality and health are by no means uniform. Cleanliness has been seen as “comely and honest” (Thomas, p. 27), as “ever deemed to proceed from a due reverence to God” whilst medieval Catholicism regarded extreme neglect of physical cleanliness as a sign of sanctity.

In the 19<sup>th</sup> century the growing acceptance and application of science as a paradigm to explain a range of phenomena meant that the connection between the individual, society, health and morality was re-conceptualised. The identification of the germ as agent of disease had massive implications not only for medicine’s understanding of health and illness but also the role of the clinical practitioner. Illness was no longer

idiosyncratic and random but could be classified with a discrete pathology. People were now diagnosed with specific conditions with an organic origin which meant that previous connections between illness and immorality were undermined. This was problematic from the point of view of controlling the health and morals of society by targeting individual behaviour (Rosenberg, 1997, p. 43). However, it was now possible to attribute disease to different groups of people with an empirical basis which had economic and political implications. Science provided the type of evidence that meant diseases such as tuberculosis came to be seen as “social scourges” rather than associated with romantic fragility and sensibility (Herzlich & Pierret, 1987). The social status of medicine as an institution, its practice of standardising care and the social and professional status of the medical practitioner were heightened as a result.

Herzlich and Pierret argue that this shift from individual to collective classifications of disease causation meant that specific illness identities began to be used to control and attribute moral states to groups in society such as the working-class. It is here that the concept of the “sick person” and Parson’s “sick role” (1951) can be seen to emerge, an illness identity which partly came about from the collective needs to have a healthy workforce, which then led to collective constructions such as “the sick”. By linking illness to the capacity to work, illness became a social phenomenon and with it the idea that people had an identity that orientated around being healthy or unwell which they had to manage when dealing with other people. Identity, beliefs and accounts of behaviour then are social categories in this view which are intimately connected to material outcomes of employment. The need to have the right identity and beliefs to participate in work was therefore a crucial issue.

Frank (1995) in his book “The Wounded Storyteller” suggests that the triumph of Modern Medicine was that people, who were previously dying, were now able to re-enter society, to be identified with “the healthy” but to be in a state of constant recovery. Frank calls this the “remission society” which include people who have had almost any cancer, on cardiac recovery programs, diabetics, people with allergies and environmental sensitivities requiring some form of dietary and other self-monitoring, those with prostheses and mechanical body regulators, the chronically ill, the disabled, those recovering from abuses and addictions, and for all these people, the families that share the worries and daily triumph of staying well. Frank demonstrates by listening to

the stories of people falling into one of these categories how society was not equipped for dealing with these new identities. If you were not wholly healthy or could be ascribed some aspects of illness you were therefore sick and possibly excluded from participating in various areas of social life. However, instead of people simply accepting the categories of sick or healthy, people in remission started to develop their own ideas about whether they were healthy or not that went beyond a medical description and diagnosis of physical symptoms. Importantly, these ideas about themselves, their own versions of self therefore quite commonly did not match the medical version.

The need for people living with chronic illnesses to adopt new ways of living, versions of themselves and beliefs meant that the relationship between morality and health was constituted in new ways. Identities, beliefs and actions relating to the different ways in which people engaged with their conditions needed to be explained and justified to healthcare professionals, family members, work colleagues etc. So instead of individuals needing to present themselves as virtuous and without sin in their explanation of the onset of disease, here morality and health were being linked to its management over a long period of time. This led to new sets of narratives being employed in which to talk about health and illness, and arguably the very concept that patients have “health and illness narratives” (Frank, 1995, pp.3-26) can be seen to emerge out of these conditions.

This focus on lifestyle, beliefs and individual actions inevitably placed individual responsibility at the heart of this moral framework. We can see how the notion of the individual as accountable has been upheld and reflected by broader cultural patterns in British society in the last 30 years. In his narrative analysis and discussion of chronic illness and the pursuit of virtue in everyday life, Gareth Williams argued that in British society in the 1980s, health, like wealth was neither good nor bad in itself. What was good was “the self-disciplined activity, which according to Protestantism and Mrs Thatcher, produces them; and in their absence is a sure sign of gluttony and sloth” (1993, p.92).

### *Connections between health, illness and morality in the 21<sup>st</sup> Century*

There is plenty of background evidence that the link between morality and health is still important today which sets the scene for a study of morality in how people with chronic illness talk about medicine taking. We can see the same relationship between individual action, beliefs and morality being constructed in health promotion initiatives in ways which have developed from the individualistic ideology Williams identifies in the 1980s. The strategy to prevent risky lifestyles can be seen through efforts aimed at specific behaviours deemed under the voluntary control of individual citizens. For example media messages such as “Smoking When Pregnant Harms Your Baby” (<http://news.bbc.co.uk/1/hi/health/2617585.stm>, Wednesday, 1 January, 2003) and campaigns to improve healthy eating using powerful images: <http://www.food.gov.uk/news/newsarchive/2009/feb/satfatcamp>.

Davison, Davey-Smith & Frankel (1991) discussed how the attempt to reduce risky lifestyles in the UK has been implemented using a two pronged approach. Driven by academics, private and public bodies in liaison with different forms of media, this has been done firstly through advertising and health promotion campaigns, and secondly by attempting to create a moral climate whereby “healthy choices are easy choices”. This moral climate ballooned more recently with the perpetuation of lifestyle programmes that present “problem cases” who undergo a “makeover” to become healthier and therefore “better” people - <http://www.channel4.com/programmes/you-are-what-you-eat/4od>. Davison argued that this promotion of individual ideologies of illness prevention orientate around self-control triumphing over self-indulgence and, in British health promotion these ideological and political debates are presented as a relatively unproblematic relationship between knowledge (awareness of information) and the decision to do healthy things (or do unhealthy things). The individual as the “reflexive consumer” is therefore armed with this knowledge and has the “free will” to adopt healthy lifestyles or not, as seen in powerful messages such as “NHS Choices. Your Health. Your Choices” (<http://www.nhs.uk/Pages/homepage.aspx>). Therefore, an ideology of the individual as decision-maker diverts attention from the social causes of illness (Crawford, 1984) and arguably creates a “discourse of responsibility” (Wellard,

1998) which needs to be managed when communicating to other people about one's health.

The relationship between individual control of one's health outcomes and choice can be seen not only in terms of responsibility over one's own health but also in terms of our responsibility to the collective needs of society. In the 1980s Williams identifies the ambiguity that people in Britain often report towards the provision of social welfare, supporting it in principle, yet finding the idea of themselves and their families being "dependent" as abhorrent. At the start of the 21<sup>st</sup> Century our collective responsibility is often seen more towards increasingly scarce and limited resources within society. With the NHS now 60 years old it is frequently portrayed as an institution buckling under the strain of increasing demands, higher expectations and limited resources "Ageing population 'will strain NHS resources", (Society Guardian, Friday December 9 2005), "Middle-age mums 'put huge strain on NHS" (The Independent, Sunday, 13 August 2006) "Superbugs drain NHS resources" (Daily Telegraph 25 January 2007). Within this discursive framework of collective and individual responsibility, users of the NHS have a moral obligation to the collective needs of society as well as to themselves to avoid putting unnecessary further pressure on clinical resources. From this perspective, the tension between individual choice on the one hand and blame and accountability on the other has arguably never been more acute.

In this discussion of morality it is clear that while in the 21<sup>st</sup> century there is a much greater discussion of the physical consequences of behaviours like gluttony, alcoholism, smoking, sexual promiscuity and cleanliness, the connection with morality is still extremely pertinent. Rosenberg (1997, p. 44) argues that the 3 basic elements of "personal"- "choice"- "lifestyle" present in today's health promotion discourse have their origins in the far older view of disease causation linking habitual sin with disease and which are linked logically, rhetorically and emotionally. As was the case in the 'pre-germ-theory' era, morality is now linked to health by quantification of cigarettes smoked, sexual partners had, alcoholic units drunk, portions of fruit and vegetables eaten. The consequences of our actions are not judged merely in terms of the physical outcomes however but also by our moral worth. This suggests that the earlier connections between morality and health are not merely consigned to history but can be seen to underpin some of the ways in which the same behaviours are viewed today and communicated across society. In other words, while there are many different ways in

which the link between morality and health has been formulated through history, there are clear patterns in the development of the language of morality and health which are communicated over time and which continue to be employed to control of the health of society.

## **D.6. An Interpretation of the ELEVATE Recruitment Process and Participants Access to Discursive Resources**

One way in which to assess the influence this recruitment process has on the research interview itself is to specify the roles that are operating in this process. Erving Goffman provides a useful analytical framework which although was designed to apply to interactional talk can be used here to emphasise the relative control over resources that the different participants have and the impact this might have on the movement of dialogue within the interaction of the research interview. Goffman (1974, 1981) in his analysis of talk discusses how, when an individual speaks there is a structuring of roles of the relative participants involved. He sets out the differing production formats that an individual may engage in when speaking and hence the differing roles that emerge as a result.

These are:

*Animator*: the “emitter” (the physical source/ soundbox in use), who can also inflect the message with personal style and intonational attitude markers (1974:518).

*Author*: the person who selects the words and meanings

*Principal*: the person who in a particular capacity/role takes/holds responsibility for the message

*Figure*: the protagonist represented in a scene described. As a figure, the speaker has enormous flexibility in the projection of his/her identity, allowing her/him to talk in a “self-dissociated, fanciful way” (1981:146-152)

Although Goffman never set out any comparable roles for the listener, Scollon (1998, p. 257) used Goffman’s framework to develop the following:

*Receptor*: the mechanical receiving of the communication (a person can repeat a message but have no idea of its meaning) (Comparable production role: animator)

*Interpreter*: derives a meaning from the communication (Comparable production role: author)

*Judge*: takes responsibility for interpretation of the meaning (Comparable production role: principal)

*Figure*: e.g. you listen differently if you are a character in a tale (Goffman 1981, p. 152).



Using Goffman's framework a straightforward interpretation of the patient's role in the recruitment process could be that they act simultaneously as author, animator, principal and figure, with a large amount of control over the meaning to be taken. However, there are a series of tools used here to apply notions of truth and objectivity regarding asthma control and quality of life to the person's experience of asthma. The questionnaires, peak flow diaries and reversibility test construct a set of linear measurements on which the person's responses have to fit. For example, question 1 of the Asthma Control questionnaire asks "On average, during the past week, how often were you **woken by your asthma** during the night?" with the available responses being "Never", "Hardly ever", "A few times", "Several times", "Many times", "A great many times", "Unable to sleep because of asthma". The use of bold emphasises that the person should only focus on being woken up and nothing else which is reinforced by the options available to them. The experience of asthma at night and its significance is reduced to a frequency of occurrence rather than anything else. This places considerable restrictions on the sorts of things that can be said and the types of interpretation that are possible. Rather than the person being seen as author here it is science that provides a limited range of words and meanings that the person can use and it is the objectivity of science that authorises evidence, fact and meaning. This authorisation of evidence means that while there is some space for the person to provide their own evaluation of their breathing difficulties, the capacity for the person to be "animator", to contribute anything unique to their responses is extremely limited.

Despite the restriction on responses available, the person with asthma nevertheless holds both the roles of "figure" and "principal". They are both the person represented within the questionnaires and breathing tests and also hold responsibility for the message being conveyed. However, where Goffman refers to the enormous flexibility within interactional talk that the figure has in how their identity is projected, there is no such flexibility here. The identity of the person is determined by a cut-off point on an average of scores, a cut-off point that the person does not have access to. This creates a paradox in that the individual plays a passive role in their identity construction of "person with inadequate asthma control and quality of life" but yet is considered responsible for that identity because of the responses that they have provided.

The role of the nurse at study visits 1 and 2 is to act as both “interpreter” and “judge” based on the clinical evidence available. However, what is being shown here is the tension between the autonomy of clinical opinion and the weight of an evidence base that assesses inadequate asthma control and quality of life based on broad generalities. The tools of objective measurement may be both an aid and a constraint to clinical judgement depending on the value afforded to that evidence by clinical guidelines, a criticism which has been made by some advocates of patient-centred medicine and which was discussed in chapter two. The clinician therefore may be judge but may also be seen as facilitator or agent to scientific fact.

Similarly, my role as Research Associate working on the clinical trial in which participants have been recruited is to act as interpreter and judge to the evidence of prescription refills and the self-reporting of adherence by the people I wanted to interview. I thereby set up my own criteria by which to judge the person and assign the identity of “non-adherent”. This assessment was based on accordance to medical assumptions which I am critiquing in my research but nevertheless this again is a categorisation that the individual had little access to when being considered for interview. The use of the Medication Adherence Report Scale as a precursor to the interview and as a prompt for discussion serves to set out the parameters for the interaction within the interview that places the person within the framework of medication adherence that I have set up.

The outcome of this process of recruitment from the participants’ point of view is that their identity is constructed in ways which they have little control or awareness. They are “person with asthma”, “person with inadequate asthma control and quality of life”, “person who has been non-adherent with their medication”. The one identity that the participant has provided consent for and therefore does have access to is “research participant”. There is a clear separation here between possible utilitarian connotations of helping society through participation in research and the clinical constructions that have been constructed from an academic perspective. What is of relevance to the analysis of interview data is how the framing of research participant influences what interviewees say and how this interacts with my own frames orientating around adherence.

## Glossary of Acronyms and Abbreviations

A&E	Accidents and Emergencies
ACQ	Asthma Control Questionnaire
AIDS	Acquired immune deficiency syndrome
BTS	British Thoracic Society
CA	Conversation Analysis
CDA	Critical Discourse Analysis
CFS	Chronic Fatigue Syndrome
DP	Discursive Psychology
ELEVATE	Acronym referring to large randomised controlled trial comparing the cost-effectiveness of two prophylactic medications for asthma
GINA	Global Initiative for Asthma
GP	General Practitioner
HIV	Human immunodeficiency virus
ICS	Inhaled corticosteroids
LABA	Long acting $\beta$ 2-agonist
LE	Linguistic Ethnography
LTRA	Leukotriene Receptor Antagonist
MARS	Medication Adherence Report Scale
ME	Myalgic Encephalomyelitis, otherwise known as chronic fatigue syndrome
MiniAQLQ	Mini Asthma Quality of Life Questionnaire
NHS	National Health Service
RCT	Randomised Controlled Trial
SABA	Short acting $\beta$ 2-agonist
SCM	Social Cognition Model
SIGN	Scottish Intercollegiate Guidelines Network
SMP	Self-Management Plan
TWOD	Truth Will Out Device

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