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**A phenomenological investigation of patients' lived  
experiences of medicines adherence: a novel  
perspective for future intervention development**

By Adam Pattison Rathbone

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Submitted as partial completion of the award of Doctorate of Philosophy to Durham University,  
School of Medicine, Pharmacy and Health

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## **Abstract**

Approximately 50% of medications are not used as prescribed, this phenomenon is known as non-adherence. The literature concerning this phenomenon focuses on reasons medicines are not taken, dissecting experiences to identify mechanisms that act as barriers and facilitators to using medicines as prescribed. Theoretical frameworks and models have been developed that conceptualise the phenomenon, enabling interventions to be established to improve medicines use. However these interventions have yet to demonstrate sustainable improvements in adherence. A novel perspective of the adherence phenomenon may direct future intervention development that will lead to improved adherence.

This project evaluated current literature concerning the adherence phenomenon; concluding that a largely 'biomedical perspective' had been taken to understanding patients' medicines use and that further work was needed that approached the phenomenon from with a novel outlook. A systematic review and thematic synthesis was conducted of evidence that, through phenomenological methods, rejected previously held beliefs and concluded that adherence was experienced by patients as an interaction between the patient's and the medicine's identity. The systematic review identified a gap in the literature that described adherence from patients' lived experiences across different disease states.

Using phenomenology, empirical research included forty-one interviews that explored patients' experiences of medicines use across five disease areas, namely cardiovascular disease, gout, chronic obstructive pulmonary disease, cancer and diabetes. This uncovered a novel description of the phenomenon as a construct of social interaction between the patient, their product and wider society (embodied as family and friends, healthcare professionals, the media and policy). Three focus groups were conducted to validate these findings and locate patients' perspectives of interventions within this novel description. Analyses from these focus groups identified that current adherence interventions represented micro-social interactions between the patient and the product, with few interventions developed that utilise patients' interactions with wider society. These works are synthesised to present new directions for future intervention development that might seek to utilise patients' interactions with friends, family, healthcare professionals and policy to improve adherence.

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## **Declaration**

This work has not been previously submitted for a degree and is not based on joint research.

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## **Dedication**

I dedicate this thesis to my grandmother, Mrs Ruby Pattison, as well as my mam, dad, brother and sister, who have taught and continue to teach me more than any of us will ever admit to. A second dedication to my fiancé, Dr Daniyal Daud, who encouraged me to embark on this work and supported me to its completion.

Last but not least, this work is dedicated to anyone who has ever missed a dose of prescribed medication, without whom this thesis would not have been possible.

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## List of terms

Word	Description
<b>Adherence</b>	How patients use medicines in relation to their prescription.
<b>Concordance</b>	An agreement between a prescriber and a patient about how medicines should, and will, be used by the patient.
<b>Compliance</b>	How closely patients' medicines use reflects the prescription. For some, this term infers superiority of the prescriber.
<b>Multi-compartment compliance aid (MCCA)</b>	An intervention that involves repackaging medicines into individual pockets, which can be aligned with a day and time of administration.
<b>New Medicines Service (NMS)</b>	A service delivered by community pharmacy contractors to promote adherence to newly prescribed medication through a brief educational intervention.
<b>Adherence Interventions</b>	Products and services that are available to facilitate medicines taking.
<b>NICE</b>	National Institute for Health and Care Excellence.
<b>Community Pharmacy</b>	A retail and healthcare space that provides pharmaceutical services, such as supplying medicines and advice, located within a specific community.
<b>Pharmacist</b>	A person who is professionally qualified to prepare and dispense medicinal drugs. In the UK, pharmacists must be registered with the General Pharmaceutical Council.
<b>Community Pharmacist</b>	A pharmacist that typically works in a community pharmacy, providing pharmaceutical services to a specific population as part of primary care
<b>Normative</b>	Describes a standard, typically in relation to behaviours but can also be applied to beliefs, values, approaches and narratives

## Chapter 1: Introduction and Literature Review

### What is adherence?

Adherence describes a phenomenon concerned with how patients use prescribed medicine. As such, the phenomenon can be argued to be as old as medicines themselves and has been reported as going back to the time of Hippocrates (Osterberg and Blaschke, 2005). Since then the concept of medicines adherence has been defined, re-defined; identified and re-identified (Ahmed and Aslani, 2014). There is often misunderstanding when defining 'medicines adherence' with 'medication compliance' and 'medicines concordance'.

Compliance has been said to infer that the patient is simply 'following orders' and complying with the wishes of their doctor. This implies a paternalistic relationship in which the patient's autonomy, choice and shared decision-making rights are not acknowledged (Cribb, 2011). As a result some healthcare professionals have avoided using this term and in 1997, the Royal Pharmaceutical Society of Great Britain (as was) suggested a discursive shift from 'compliance' to 'concordance' (Mullen, 1997, Royal Pharmaceutical Society of Great Britain, 1997). Concordance was preferred, as this term implies that there is an agreement between the patient and the practitioner about how prescribed medicines will be used.

Despite semantic difficulties, current estimates indicate that between 30-70% of medicines are not used as prescribed, however this figure varies greatly depending on the context and the measure used (Haynes et al., 2008, World Health Organisation, 2003). A wide variety of methods exist for measuring adherence, including self-report techniques, electronic monitoring of adherence, pharmacy administrative data, observing clinical effectiveness, measuring blood concentrations of medication and newer techniques that utilise tracking technology and health apps (Haynes, 2001, Proteus Digital Health Inc, 2015). Whilst many methods of measurement exist, policymakers accept that non-adherence is common, demonstrated here by The National Institute for Health and Clinical Excellence (2009) that argued that in order to support adherence 'healthcare professionals must recognise that non-adherence is common and that most patients are non-adherent sometimes' - although the precise meaning of 'sometimes' in this context is ambiguous.

Non-adherence is common across disease groups, with adherence reported as low in diabetes (Asghari et al., 2010), in cardiovascular disease (Banik and Ray, 2012, Bane et al., 2006, Hagström et al., 2005) and to inhaled therapies (Cecere et al., 2012).

***Defining adherence: a case of semantics or ontology?***

The definition of adherence can be interpreted as an area of contention within the literature. Many professional bodies and healthcare organisations have contributed to the medicines adherence debate in defining the phenomenon (Cribb, 2011, National Institute for Health and Clinical Excellence, 2009, Royal Pharmaceutical Society of Great Britain, 1997, World Health Organisation, 2003, Nunes et al., 2009, The Audit Commission for Local Authorities and the National Health Service in England and Wales, 2001). Health reform across the globe, centering on improved patient outcomes rather than traditional models of healthcare delivery, have made defining, measuring and improving medicines adherence a focus of academic and clinical discussion (Rosenbaum and Shrank, 2013). Yet this relatively modern interest is underpinned by an historical context – reportedly going back to the time of Hippocrates (Osterberg and Blaschke, 2005). Since then defining the concept of medicine adherence has been a subject of academic interest (Ahmed and Aslani, 2014). Within the literature, there is often overlap when defining ‘medicines adherence’ with ‘medication compliance’ and ‘medicines concordance’. As outlined above, compliance is considered to give prescribers more ‘power’ than patients, implying a paternalistic relationship in which the patient’s autonomy, choice and shared decision-making are not fully acknowledged (Cribb, 2011). As a result some healthcare professionals have been directed to avoid using this term, preferring to use the terms ‘concordance’ or ‘adherence’ (Mullen, 1997, Royal Pharmaceutical Society of Great Britain, 1997). Concordance is argued to imply that there is an agreement between the patient and the practitioner about how their prescribed medication will be used. However, work by Dingwall and Pilnick (2011) argue that asymmetry in knowledge and power prevents patients from adopting the role of an equal decision maker. This suggests the term concordance might not appropriately reflect the reality of the prescribing process or adherence phenomenon. Adherence, as a term, has grown popular over the last decade in an attempt to avoid subjective assumptions of patients’ behaviour, emphasising how closely medicines use ‘sticks’ to the prescription. Variation in semantics appears to be further compounded by variation in the ontological basis of what adherence is.

### ***Definition, dissection, quantification***

Changes in ontology can be inferred across the literature over time and between publications. Authors writing about medicines adherence typically begin by defining their interpretation of the phenomenon. For example, Osterberg and Blaschke (2005), describe medication adherence as ‘the extent to which patients take medications as prescribed by their health care providers.’ The World Health Organisation defines adherence differently, adding more complexity to the phenomenon, as ‘the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider’ (World Health Organisation, 2003). A Cochrane Review uses another variation, defining adherence as ‘the extent to which patients follow the instructions they are given for prescribed treatments’ and adding to the definition by attaching a numerical value to the concept, adding ‘thus, if a person is prescribed an antibiotic to be taken as one tablet four times a day for a week for an infection, but takes only two tablets a day for five days, his /her adherence would be  $(10/28=)$  36%’ (Haynes et al., 2008). The addition of a calculable, numerical value to the description may have represented a shift in the ontology of the phenomenon – rather than being concerned with beliefs or a set of behaviours, there is greater focus on objective measures of a task.

The objective measurement of adherence presents further ontological issues. For example, is non-adherence identified after missing just one dose or many? What counts as missing a dose – missing it by five minutes, fifteen minutes or fifty? Further objectification appeared in the literature as a reconceptualization of the phenomenon, giving rise to terms such as ‘persistence’ and ‘discontinuation’. These concepts pertain to the duration of treatment whereas previous definitions appeared to describe the day-to-day process of medicines use (Cramer et al., 2008, Cramer et al., 2007). Others argue that adherence can be dissected further into ‘initiation’, ‘implementation’ and ‘discontinuation’ (Vrijjeans et al., 2012), enabling adherence to be calculated discretely across time. The deviation and separation of different components of the phenomenon in the literature represents a dissection of the ontology of adherence, adopting a scientific, and almost biomedical approach, to the phenomenon by identifying component parts to understand the whole.

A common dissection in the literature is intentional or unintentional adherence (Clifford et al., 2008), further stratification can be made, not only into adherent and non-adherent, but also in terms of poor, satisfactory, good, very good and excellent. In this sense, intentional

and unintentional adherence engenders patients as active decision makers, choosing to adhere or not (Simpson et al., 2006). Attaching numerical values to these labels enables adherence behaviours to be quantified, which can then be used to position the patient within pre-defined categories of adherence thresholds. As patients move up and down an ordinal scale, adherence can be stratified as a range from poor to perfect, however due to the pre-determined (and sometimes arbitrary) thresholds, in some instances patients can be classified as non-adherent by one classification system and poor adherers by another (Haynes et al., 2008). This dissection and classification is argued to enable the phenomenon to be considered scientifically, as an objective representation of the experience.

The phenomenon as a whole however, appears to be confused by these dissections and reclassifications, with some, as in the case of 'compliance' and 'concordance', shifting power from the prescriber to the patient. These shifts are also evident in the literature. In 2009 NICE reported that in order to support adherence, healthcare professionals must 'recognise that non-adherence is common and that most patients are non-adherent sometimes' (National Institute for Health and Clinical Excellence, 2009). Controversially for some, these guidelines direct responsibility for non-adherence towards professionals, 'non-adherence is a large problem, but it should not be seen as the patient's problem. Rather, it represents a limitation in the delivery of healthcare.' This generates a paternalistic ontological position, where patients are passive (as opposed to active) medicines users. Other guidelines recommend and advocate patient involvement in decision-making about using medicines, further confusing the ontology of adherence in terms of responsibility and accountability. Indeed other positions state 'patients should not be blamed for the problems they experience in medicines taking' (York Health Economics Consortium and School of Pharmacy, 2011). Apportioning blame and responsibility to the phenomenon, pulls the definition of adherence away from an objective numerical value and towards a moralistic or social perspective.

### ***Positivist definitions***

Rather than consider this more moralistic perspective however, accepted definitions within the literature remain focused on objectification of adherence and dissection of the phenomenon. Much of the research base has focused on identifying general barriers or facilitators to individuals' adherence. The proposition is that by removing the barriers or increasing the facilitators, adherence can be improved. This approach is not-too-dissimilar to biomedical conceptualisations of disease progression. For example, as patients move

through different stages of a disease, they have different experiences and physiologically different processes are happening. Pathophysiology is increasingly understood through research that dissects tissue, with biological processes or targets identified and treatments developed. Adherence appears to have been approached in a similar way, dissecting the phenomenon metaphorically, with different social, psychological, biological, and economic constructs identified as barriers and facilitators of adherence and non-adherence. From this almost wholly biomedical perspective, adherence is posited as an ideal or an 'ideal truth', which can be worked towards and achieved, like a measure of blood pressure or temperature, through manipulation of barriers or facilitators. This ontological position in the literature is underpinned by biomedical or psychological 'stimulus – response' paradigm. A syllogistic view of a directly observable response in medicines taking is commonplace yet deductive reasoning of this kind appears to have failed to deliver interventions that improve long-term adherence.

Epistemological positions that identify 'ways of knowing' have underpinned the development of multiple methods of measuring adherence (Bauer et al., 2013, Weinstein et al., 2011, Asche et al., 2011). Methods of measurement have included assessing the different levels of dosing irregularities or measuring gaps in treatment from a range of measures, including: pharmacy-claims data, reviewing administrative claims; pill counts; calculating medication possession ratios; administering Morisky Medication Adherence Scale (MMAS); calculating Proportion of Days Covered (PDC); self-management profiles; administering Brief Medication Questionnaire; electronic packaging to record when a medication is opened; five-item Medication Adherence Report Scale (MARS-5); electronic diaries and dose-counters; pill-cap monitoring or Medication Event Monitoring Systems (MEMS); Real Time Medication Monitoring; self-reported levels of adherence or a mixture of multiple methods.

Whilst variation is often favoured in research, providing methods of triangulation and validation, a downside is that such variation may impact the underlying conceptualisation of the phenomenon, particular when findings are transferred or generalised. For example when adherence is measured using prescription refill data, the phenomenon of adherence, might be understood only as the supply or collection of medicines, a symbol perhaps of the intent to adhere, rather than of the act of adherence. Another example may be a self-reported questionnaire, here adherence might be ontologically positioned as a construct of the patients belief or memory, rather than a physical act of collecting or taking a

prescription medicine. These epistemological differences further compound and confuse the literature as to the ontological nature of adherence.

In addition to the definitions reported by academics, professionals and policy makers, what is conspicuous by its absence in the literature is the definition used by patient groups. Very few patient groups appear to have been involved in constructing definitions of adherence to medication and a 'man on the street' [sic] test may show that few patients are actually familiar with the concepts or terms of 'medicines adherence', 'medicines compliance' and 'medicines concordance'. This lack of a patient voice in the ontology of this area may mean that patients have not been involved in the development of understanding adherence or the development of interventions to improve adherence. This suggests that the adherence literature is continually framed from the perspective of those doing the research, typically healthcare professionals, psychologists, and scientists. This highlights a gap in the literature for work that defines or describes the phenomenon from a perspective that is separated from the previously held presuppositions and beliefs of adherence researchers.

### **Reasons for non-adherence**

Ontological underpinnings of adherence have fed into models of adherence that locate a number of various constructs as key facilitators or barriers to adherence. Interpretation of the broad literature here infers that much research has been conducted within paradigmatic silos that have focused on the phenomenon from a narrow perspective, such as a specific disease group or specific barrier or facilitator. This disintegration of the phenomenon could be argued to have drawn attention away from understanding of the phenomenon as whole. As a consequence many reasons for non-adherence that are reported in the literature are within specific social, economic or disease contexts, arguably limiting their transferability to an individual patient in practice. Reasons for non-adherence that appeared in the literature are evaluated below.

#### ***Ethnicity, age and gender***

A systematic review found similar reasons for non-adherence in different countries, however concluded that ethnic minorities were less adherent (Gebregziabher et al., 2011), suggesting interventions to be culturally adapted. On evaluation, ethnicity does not lend itself well to a dissection of the phenomenon through statistical modelling. Quantitative research cannot consider all of the factors associated with ethnicity and thus patients become categorised as simply 'white' or 'black' or 'other'. Ethnicity can be described as more than the colour of a person's skin, as it is often stratified in quantitative studies, and

rather embodies language, culture, family, neighbourhood, poverty, housing, literacy and religion, which all come to bear within a person's ethnic identity. The social factors that intersect ethnicity appear to be subsumed within categorical values, enabling statistical analysis of ethnic subgroups, which show statistical differences in levels of adherence. However often the underlying cause of the difference, as addressed by qualitative research, shows similarities in barriers and facilitators to adherence across ethnicities and cultures (Marshall et al., 2012). Any difference that does occur in the literature seems to be mediated by the relationship with the healthcare provider; i.e. if the provider is ethnically concordant with the patient (Traylor et al., 2010) or mediated by health literacy. A systematic review in 2011 was unable to determine if ethnicity does influence adherence due to the heterogeneity of the data selected for inclusion (Peeters et al., 2011).

Age is often reported to influence adherence. Older (>70 years) and younger (<50 years) ages are associated with lower adherence, compared with middle-aged patients (50-69 years) (Mann et al., 2010). Younger age has been associated with poor adherence in type one diabetes, but good adherence in hypertension and dyslipidemia. Whilst specifically to thienopyridines, such as clopidogrel, in cardiovascular disease, younger age correlated with poorer adherence (Nigam et al., 2012). However older-age has been shown to reduce the effect of good adherence on positive clinical outcomes, but has also been shown to positively correlate with adherence in a number of studies (Rolnick et al., 2013). Within this literature, the influence of age on adherence does not appear to appreciate the complexities involved in ageing and natural disease progression, often over simplifying poor adherence as a symptom of old age or morbidity. This demonstrates the disintegration of the literature, in that whilst providing evidence for specific groups of medicines or patients, the role of age within the experience of adherence remains difficult to determine.

The role gender plays in adherence is also conflicting; arguably females are more adherent after retirement in certain areas however a number of studies argue men are more adherent prior to and after retirement (Hertz et al., 2005, Davies et al., 2013, Khanna et al., 2012). Evidence framed by disease state (namely hypertension, COPD and diabetes) shows that gender was not found to result in statistically significant differences between genders (Matsumura et al., 2013) although other authors argue females are more likely to be intentionally non-adherent to their COPD medication, how this can be translated to other disease areas remains unknown. Other work argues that males may have their own issues

with adherence, due to difficulty in the integration of illness with their masculine identity, leading to difficulties in taking medicines as prescribed (Hagström et al., 2005). In these studies gender is situated biologically, as male or female, without considering gender as a psycho-social construct, it is considered as a biological proxy. Here too, as in ethnicity and age, the literature is conflicting and limiting the ability to understand the adherence phenomenon across different contexts.

Similarly, socioeconomic factors differ regarding their influence over adherence with some studies suggesting they have an impact - usually a positive correlation between adherence, education and income (Mann et al., 2010) and others suggesting no difference (Kivimaki et al., 2013). Some argue the social constructs that enable age, gender and ethnicity to be identified and understood are the reasons any difference in adherence is seen, rather than being due to biological classifications of age, gender and ethnicity (Tantikosoom et al., 2011). Arguably these constructs may have an influence on adherence, however this influence has thus far failed to be demonstrated consistently in the literature. At best, this literature informs how practitioners might predict adherence behaviours, at worst it generates prejudices that might damage practitioner and patient relationships.

### ***The patient, their medication and their disease***

Adherence was often described as a negotiation between the patient, their medication and their disease. This literature often considered patients' understanding of the purpose of their medication (Horne and Weinman, 1999) and as above, often research was conducted within a specific patient group, to a particular medication or medication class and within certain disease contexts. For example in patients with cancer, the specific medication used was shown to influence adherence (Streeter et al., 2011), however this is likely to be linked to the tolerability of chemotherapy, and might not be easily applied to medication in other disease contexts, such as differences between adherence to ibuprofen and paracetamol. Patients' sense of satisfaction was shown to be a significant predictor of adherence to COPD medications in Spain and the UK, but satisfaction only had a moderate impact on adherence in France, Italy and Germany – generating questions about patient expectations, culture, and access to treatment more than answering questions about patients' medicines use in COPD. For patients with diabetes injection-related discomfort was considered a source of patient-reported anxiety that may contribute to non-adherence (Fu et al., 2009) without considering anxiety that may be experienced due to negative health and socioeconomic outcomes of a diagnosis. For example, barriers to adherence in

hypertensive patients in the United Arab Emirates included health beliefs rooted in a lack of information about their disease, in cultural practices and in relationships with family, friends and the health system (Alqasem et al., 2010). Further research highlights the positive impact newer methods of insulin delivery, including inhalation, can have on adherence (Baser et al., 2010) and healthcare costs – however this research does not appear to adequately consider how such technological innovations might be applicable to other disease or patient contexts.

Literature investigating patients' perspectives of medicines use report dynamic and varied findings. Here too the literature demonstrates work carried out in disease specific settings (Jin et al., 2008, De Vera et al., 2013, Farooqui et al., 2011, Gordon et al., 2007) although in many instances patients' perspectives appear transferable across disease groups, for example Gordon et al. (2007) report patients' concerns of side effects in cardiovascular disease, which are mirrored in Farooqui et al.'s (2011) and Jin et al.'s (2008) work on cancer and gout respectively.

A minority of literature considered facilitators and barriers to adherence from more than one perspective, for example the duration of the prescription appeared to influence adherence to oral anticancer treatment (increased duration, decreases adherence) as well as in other diseases areas (Partridge et al., 2003, Cheah et al., 2013). Patients have been shown to be more adherent to medication for pre-existing conditions (hypertension and diabetes) than to medication prescribed for more recently prescribed conditions although the mechanism or mechanisms underpinning these findings are unclear. In the study investigating views about co-morbid diabetes and cardiovascular disease, authors concluded that patients were sceptical about the addition of new medicines, with more importance given to diabetes medication rather than medications for cardiovascular disease, with lipid-lowering agents given the least importance (An and Nichol, 2013). Further research confirms that patients are at higher risk of non-adherence with statins compared to anti-hyperglycaemic agents, suggesting variation between medications within the context of multiple disease states (Zhang et al., 2011).

Whilst a minority of work was conducted in patients with multiple diagnoses, the majority of studies were conducted in disease specific groups, highlighting a gap in the literature of studies that consider adherence across disease groups. What is unclear from this literature is if barriers and facilitators to adherence that have been identified within these patient-specific, medication-specific and disease-specific contexts are transferable to other

contexts to support patients' medicines taking across different settings. Work identifying the transcendental structures of the experience, which are essential to the experience of adherence, across different disease contexts and in different patient groups, using different medication, have not yet been identified.

***The prescriber, the pharmacist and cost***

The influence the prescriber has on adherence is well documented in the literature (Gault et al., 2013, Traylor et al., 2010), ranging from the prescriber's education (Cooper, 2002) to some patients comparing their prescribers' instructions to those from God (Stewart et al., 2013). Interventions that are pharmacist-led showed significant promise in improving adherence although why this occurred remains unclear (Ryan et al., 2011, Hung, 2013, Mehuys et al., 2011, Khmour et al., 2009). A Cochrane review concluded that pharmacist-led interventions could improve adherence (Lindenmeyer et al., 2006) however further research is needed to understand how this interaction is located within broader perspectives of the adherence experience. Other research has shown that some pharmacy services, namely the 'repeat prescription service', were reported to confuse patients and make patients less likely to engage in treatment (Beattie, 2007). By removing patients from the ordering process of medicines, it could be argued that their responsibility and investment in the medicines taking process has been reduced, making them less likely to engage with treatment.

The financial cost of picking up prescriptions or paying for prescription medicines at the point of collection appeared to influence the way medicines are used; the higher the medicines cost, the less likely patients are to collect their medicines however in some cases an increased cost, and perception of cost, improved medicines adherence (Bowry et al., 2011, Dunlay et al., 2011, Castaldi et al., 2010, Dolce JJ et al., 1991) – highlighting disparity between research in specific contexts. In one study, patients reported cost-related non-adherence to cholesterol-lowering agents compared to symptom-relief medication and another study has demonstrated that the influence of cost is mediated by the number of co-morbidities a patient has (Wang et al., 2011) suggesting work that considers adherence within the specific context of cost may miss broader experiences of adherence. This conflicting body of literature highlights the importance of the context of medicines taking as a high-cost drug may improve adherence in one setting and reduce adherence in another. Indeed cost must be considered carefully in light of the varying payment structures for medicines across the world.

Whilst many reasons for non-adherence exist within the literature, there was unified approach that appeared to bring facilitators and barriers together. Rather the literature suggests a dynamic interaction between multiple factors, barriers and facilitators across biological, psychosocial and economic platforms within a multitude of different contexts. Further empirical work is needed to describe how these constructs sit together within interactions of daily life, such as interaction with family, friends, the media and the Internet as well as interactions with specific products, disease states and patients. A reductionist approach has led to the dissection of the phenomenon into facilitators and barriers and the construction of theoretical models that describe the whole by synthesising constitutive parts.

### **What happens when patients are non-adherent?**

Patients who do not use medicines according to a prescription are at increased risk of mortality, hospitalisation, disease progression and wastage of medicines and associated resource. However, increased adherence to prescription medication can also lead to increase healthcare expenditure and increase patient experiences of side effects.

#### ***Increased morbidity and mortality***

A study from 2012 reported that more than 125,000 people die in America each year due to medication use that deviated from the prescription (Banik and Ray, 2012). Lower medication adherence increases hospitalisation, with up to 20% of acute care hospital visits in the United States associated with non-adherence (Davis et al., 2012, Heaton et al., 2013, Simoni-Wastila et al., 2012, Stuart et al., 2010). Mortality is significantly increased in diabetes, cancer and a range of other diseases including COPD - with almost double the number of patients defined as poor adherers dying in one randomised control trial (Currie et al., 2013, Han, 2009, Simpson et al., 2006, McCowan et al., 2008). Studies have also shown that adherence to medication produces statistically better clinical outcomes, contributing to reduced mortality rates, across a range of diseases, including cardiovascular disease (Matsumura et al., 2013), diabetes (Al-Qazaz et al., 2011, Hong and Kang, 2011, Currie et al., 2013, Evans et al., 2011); chronic obstructive pulmonary disease (Vestbo et al., 2009, Han, 2009); cancer (Geynisman and Wickersham, 2013, Marin et al., 2010, McCowan et al., 2008); and in meta-analyses across disease groups (Simpson et al., 2006). Indeed other work locates non-adherence as leading to increased severity of illness and

impact on a person's quality of life (York Health Economics Consortium and School of Pharmacy, 2011, National Institute for Health and Clinical Excellence, 2009)

Additionally, there is a growing body of evidence to support the concept of a 'healthy adherer', with clinical trials reporting improved outcomes in patients who adhere to both placebo and the test drug (Han, 2009), some studies now control for 'healthy adherer' bias. Despite this, the link between mortality and adherence is not considered tenuous and is best described in a quote from the US's Surgeon General, "medicines don't work in patient's who don't take them," (Osterberg and Blaschke, 2005).

### ***Increased financial waste***

Many professional bodies and healthcare organisations have identified poor adherence as a global cause of negative health outcomes and financial waste (National Institute for Health and Clinical Excellence, 2009, Royal Pharmaceutical Society of Great Britain, 1997, World Health Organisation, 2003, Nunes et al., 2009, The Audit Commission for Local Authorities and the National Health Service in England and Wales, 2001). Despite some studies reporting correlation between adherence and increased health expenditure by consumers and governments (Breitscheidel et al., 2009), poor adherence is most commonly reported to lead to financial waste (Carls et al., 2012, Stuart et al., 2012, Balkrishnan et al., 2003).

Wasted medication in the National Health Service in England account for approximately £300 million annually (York Health Economics Consortium and School of Pharmacy, 2011), tying this into adherence, Carls et al. (2012) showed that adherence is also linked to significant economic loss. The authors argue that adherence lowers healthcare costs as it prevents more serious and expensive treatments later on in the patient's life (Lee et al., 2006, Hong and Kang, 2011, Balkrishnan et al., 2003, Egede et al., 2012, Jha et al., 2012, Salas et al., 2009, Simoni-Wastila et al., 2012, Stuart et al., 2011, Wild, 2012, Zhao et al., 2011). However other researchers argue that increased adherence increases expenditure, as more medication needs to be purchased for patients to consume (Asche et al., 2011, Breitscheidel et al., 2009, Cheng et al., 2013, Hansen et al., 2010, Stuart et al., 2013). A literature review by Foley et al. (2012) concluded that 81% of studies assessing cost and adherence found a statistically significant reduction in healthcare costs for increased adherence, suggesting increased expenditure may be outweighed by costs saved from preventing illnesses.

Although not all attributable to poor adherence, a joint report by the York Health Economics Consortium and the School of Pharmacy, University of London concluded, in England waste medicine represents £90 million of unused prescriptions medicines retained in homes at any one time, an additional £50 million of medicines is wasted by care homes and £110 million of medicines are returned to pharmacies annually. The authors state this is an underestimate due to methodological flaws of the research method used to obtain the figures and go on to say that ‘cost effective waste reduction techniques’ may only deliver marginal cost reduction due to the multiple causes of non-adherence (York Health Economics Consortium and School of Pharmacy, 2011). Considering that improved adherence may lead to the improved health of a population, it stands to reason that improving non-adherence will result in an overall economic saving as the population remains healthier for longer or recovers from illness sooner – potentially improving productivity through reducing absenteeism and improving productivity. Understanding this phenomenon such that interventions can be developed, which support adherence, therefore has significant economic value.

Given the opportunity cost of improving medicines adherence is likely to be in excess of £500 million per year (York Health Economics Consortium and School of Pharmacy, 2011), representing a considerable sum, governments and health organisations have been keen to identify common patterns and reasons for non-adherence.

Many reasons for adherence and non-adherence have been identified. This makes it difficult to delineate clear constructs that are important to the experience of adherence. Literature, both qualitative and quantitative, that describes reasons for adherence and non-adherence are often contextualised within a specific setting – such as patient group or disease (Munro et al., 2007, DiMatteo, 2004). Despite work often being conducted in context specific silos, adherence is understood as a construct of patients’ physical ability to consume medicines and patients’ beliefs about medicines.

The predominant framework describing adherence is known as the Necessity-Concerns Framework (Horne, 2005). This framework posits medicines use as an individual risk-benefit appraisal of medicines used based on constructed perceptions about medicines and disease as part of the Beliefs about Medicines Questionnaire. When patients perceive medicines as more dangerous than beneficial, non-adherence is predicted. Conversely when medicines per se are considered more by the patient to be more beneficial than they are dangerous, adherence is predicted. The National Institute of Health and Care Excellence

(NICE) describes reasons for non-adherence that are underpinned by a distinction of the phenomenon into domains of intentional non-adherence, where the patient's beliefs about medicines or their disease direct them to avoid using medicines as prescribed, and unintentional non-adherence, where patients' beliefs about a medicine or their disease direct them to take medicines as prescribed however due to external factors they are unable to (Nunes et al., 2009). Here external factors describe practical problems associated with the physical enactment of taking medicines, such as forgetfulness, being physically unable to open containers, and accessing medicines due to shortages or healthcare structures. Whilst reasons for non-adherence can be stratified into two broad themes, much of the research that has investigated adherence is underpinned by biomedicalism, whereby phenomenon are dissected and understood as constituent parts of the whole. For example some research is targeted to patients in specific disease groups, making it difficult to transfer these findings to patients in other disease groups and develop interventions that might benefit broader populations.

Whilst interventions may represent a paternalistic construct of the biomedical sphere, many interventions promoting adherence exist and these are often developed based on a particular conceptual or theoretical perspective that describes reasons for non-adherence. For example, interventions that attempt to educate patients about medicines might be based on frameworks that posit medicines use as a construct of patients' beliefs. Alternatively interventions that attempt to remind patients to use medicines might be underpinned by approaches that locate medicines use as a function of memory. Whilst there appears to be theoretical congruency between current interventions and philosophical understanding of adherence, only a limited number of interventions have demonstrated improvements in adherence or patient outcomes. For example an intensive intervention included supplying participants with pill containers, reminders, counselling, and feedback by a dedicated team of staff improved adherence in uncontrolled hypertension (Haynes et al., 1976). Equally in patients with diabetes, bi-weekly telephone calls and educational follow-up interventions improved medicines adherence (Piette et al., 2000). Whilst these interventions demonstrated improvements in specific disease contexts, meta-analyses across disease groups has yet to demonstrate sustainable improvements in adherence (Haynes, 2001, Nieuwlaat et al., 2014) – suggesting that further work is needed to understand the phenomenon and direct the future development of interventions across disease groups.

That adherence interventions have been developed within specific disease contexts (Vervloet et al., 2012), may demonstrate the dissection of the adherence phenomenon to reflect variation in somatic experiences of illness across disease states. For example patients with cardiovascular disease and type two diabetes may be unaware of their illness for many years, where as patients in more acutely symptomatic contexts, such as gout or chronic obstructive pulmonary disease, may be more aware of their illnesses. In other disease contexts, such as cancer, pharmacotherapy may generate adverse events that are more severe than initial symptoms of the disease. These differences between disease settings have directed intervention development to specific patient groups, as evidenced above. However a preliminary evaluation of an intervention that focuses on the initiation of medicines, the New Medicines Service, that is theoretically underpinned by a model of adherence based on individual patient's beliefs about their medicines and disease, delivered on a societal scale (i.e. it is commissioned nationally) is reported to improve adherence significantly (Barber et al., 2004, Clifford et al., 2006, Elliot et al., 2014). Whilst this more recent work still represents a one-to-one interaction between the pharmacist and the patient the commission approach suggests that future interventions may need to transcend diagnosis, focusing less on disease context and rather on approaches to medicines use at a societal level. Further work is therefore needed to present a novel perspective of adherence that describes patients' lived experiences of adherence across disease states that might direct future intervention development.

### **Theoretically framing adherence**

Whilst varied definitions appear to have driven the research of barriers and facilitators to adherence, constructing the reasons for non-adherence outlined above, conceptual modelling of the phenomenon also appears in the extant literature. Reasons for non-adherence have been synthesised, condensed and moulded into theoretical frameworks or conceptual approaches. Here the dissected parts of the phenomenon are reconstituted to represent the whole, in a way that enables adherence behaviours to be predicted within a positivist paradigm. Reconstructing a representation of the whole however has led to the construction of theoretical framings that characterise adherence from specific, rather than general, ontological perspectives. For example. one model outlined by Dowell and Hudson (1997) classifies patients as passive acceptors, active users or all-together rejecters with adherence influenced by multiple constructed facilitators such as 'faith in the prescriber', 'knowledge' and 'acceptance of the disease' with practical issues of physically taking

medicines given lesser emphasis. This further clouds the ontology of adherence, raising question as to the underpinning essence of the phenomenon within constructed models.

Models of adherence are varied and only a handful of key models are discussed below to demonstrate the broader perspectives of understanding medicines adherence. These models are tabulated in Appendix A, but for completeness other models that have been used to investigate adherence include Self-Determination Theory (Li, 2010, Williams et al., 2009), Peer-Crowd Peer-Support Model (Fleischman, 2013), Social Action Theory (Gore-Felton et al., 2005), Information-Motivation-Behavioural Skills Model (Zarani et al., 2010), Coping Theory (Garay-Sevilla et al., 2011), The Self-Efficacy Model (an adjunct to The Health Belief Model) (Girdwood, 2008), Kleinmann's Explanatory Model (Lai et al., 2007), The Trans-theoretical Model (outlined by Donyai, 2012), The Self-Regulation Model (Leventhal et al., 1992a), Integrated Model of Behaviour Prediction (Ruppar, 2010), The Ecological Health Systems Model (Ruppar, 2012) and Cognitive Orientation Theory (Nurymberg et al., 1996). As demonstrated by this extensive but not exhaustive list there is current debate about how adherence, and health behaviour encompassing adherence, should be modelled and conceptualised.

The Theory of Planned Behaviour models behaviour on intentions (Manning and Bettencourt, 2011). Patients who had long-term plans had better levels of adherence, using constructs such as 'locus of control', 'financial instability', and 'trust in the provider' as keys to achieving adherence outcomes (Atkins and Fallowfield, 2006, Edwards, 2011, Kohlmann et al., 1993). This defines adherence as a phenomenon of intentionality. Another example might be the Fuzzy Trace Theory (Reyna, 2008), which identifies experiences and decisions about medicines use as subjective, based on patients' own conceptions, beliefs, knowledge and skills. This theory utilises the concept of 'heuristics', which could be considered as rules-of-thumb, describing patients' knowledge as either 'verbatim' or 'gist'. Within this theory is recognition of patients' experiences of remembering the 'gist' of information about medicines, and whilst raising questions about patients' construction of 'gist' and 'verbatim' knowledge, this theory locates medicines taking as ontologically based in memory or cognition as a whole.

The Necessity-Concerns Framework alternatively describes adherence as a relationship between the patient's perceptions of posited need to take the medicine and concerns about taking the medicine. Measured on an ordinal scale, the patient's perceived levels of need and concern can be measured and compared to predict adherence; poor adherence is

predicted when participants have low necessity scores and high concern scores, with good adherence predicted when participants have high necessity scores and low concern scores (Horne et al., 2013, Stack et al., 2008). Within the framework, patients' perceptions of need are considered as posited in reality, discoverable, observable and 'out there' ready to be found, supporting a definition of adherence that is based on patients' beliefs rather than an ability to remember to and/or physically utilise medicines.

Wu et al. (2008) conceptualises adherence through linking multiple factors together, such as 'knowledge about the disease' to 'symptoms', and 'symptom control' to 'medicines use', in relation to constructed factors such as 'the prescriber, family and environment' and 'habit-forming activities'. Whilst acknowledging there may be some interaction between targets, this position still supports a dissection of the experience into facilitators and barriers that result in a posited, normative outcome, rather than describing the experience as a whole.

## **Intervention development**

As outlined above, the evidence base has focused on identifying reasons for non-adherence that are categorised as facilitators and barriers within different theoretical frameworks. The literature demonstrates that these theoretical constructs have underpinned the development of interventions, supporting the 'interventionalisation' of the phenomenon which in and of itself represents a positivist approach, here refers to an agenda that seeks to improve medicines adherence through various interventions embodied as products or services. In a similar way to developing pharmaceutical products, understanding pathogenesis is a key to identifying targets for interventions. Identification of a target in drug development might be an active site in an enzyme or a receptor on the surface of a cell, however in relation to facilitators or barriers to adherence the literature is conflicting. Within the evidence base a single target can encompass many different parts of a patient's life, linking barrier to facilitator and in some instances the two switch; a former barrier becomes a facilitator to good adherence and *vice versa*. For example, polypharmacy has been shown as a barrier to adherence, confusing patients with a high pill burden and resulting in non-adherence, yet there is a bulk of literature supporting the argument that polypharmacy might also improve adherence through a habit-forming mechanism (Williams et al., 2008, Virdee et al., 2013, van Bruggen et al., 2009, Tam-McDevitt, 2008, Chen et al., 2013, Adisa and Fakeye, 2013). Polypharmacy then may not readily present itself as a target for intervention development – yet products and devices are reported in

the literature that have done so (Virdee et al., 2013, Salam et al., 2013, Devabhaktuni and Bangalore, 2009, Bryant et al., 2013). This represents a disparity between understanding adherence at an ontological level through conceptual frameworks and the development of targeted interventions to improve adherence in the evidence base.

Interventions in the literature appeared to be based on findings in specific contexts, yet applied to broader groups of patients without necessarily considering theoretical boundaries. The relatively narrow focus of intervention development in the literature highlights that intervention development tends to focus on adherence in one disease group or based on one specific barrier or facilitator of adherence. In turn this has led to the development of interventions that are narrowly focused. This approach speaks to the Integrative Model (Fishbein, 2008), which is made up of the Theory of Planned Behaviour, Reasoned Action Approach and Theory of Reasoned Action. It argues that behaviours are more likely to change if they are specific, thus rather than being concerned with 'improving health' or 'lowering blood pressure', behaviour change interventions are more successful if they are targeted to specific activities, within specific contexts and times, such as 'taking a pink pill, first thing in the morning, everyday for a week'. This theory typifies the approach to intervention development present in the literature, whereby interventions appeared to be developed in specific contexts.

Despite many different types of interventions being developed, very few of these studies reported any sustained improvement in adherence that resulted in significant clinical improvements or improvements in patient satisfaction or experience (Haynes et al., 2008). This may be as a result of interventions being developed within contextually specific spheres that limit transferability or generalizability to other settings, or be a result of differing ontological and epistemological perspectives of the phenomenon.

### ***Information and education***

Information and education interventions are products and programmes that aim to provide patients with broad and deep information about their medicines and the conditions for which they have been prescribed. Interventions of this nature range from information leaflets to patient-practitioner consultation (Touchette and Shapiro, 2008). They are, broadly, based on the models of adherence that focus on patients' attitudes, such as the Theory of Planned Behaviour, Fuzzy Trace Theory and Necessity Concerns Framework, outlined above.

Successful educational tools have been developed to target the educational issues contributing to non-adherence in patients with low health literacy and type two diabetes as well as those patients with a primary or secondary indication for statin therapy (Negarandeh et al., 2013, Nieuwkerk et al., 2012), which slightly increased levels of adherence. Interventions aimed at altering beliefs or perceptions about medicines as well as the consequences of disease may improve adherence, indeed 2-hour long interventions based on informing patients and motivating patients to use medicines as prescribed, showed promise in improving adherence in cardiovascular patients (Zarani et al., 2010).

However when transferred to different disease settings educational tools appeared to be less successful; behavioural and educational interventions in epilepsy have proven inconclusive (Al-aqeel and Al-sabhan, 2011). Indeed interventions within the same disease context, but different setting failed to demonstrate improvements in medication adherence however did, surprisingly, demonstrate improvements in clinical outcomes (Tapanya, 1997) suggesting clinical outcomes might be improved due an unknown mechanism. Due to heterogeneity of data, a Cochrane Review and narrative synthesis concluded that educational interventions were inconsistent in their improvement of adherence (Ryan et al., 2011) suggesting as interventions move from setting to setting, locating the intervention within new contexts presents issues.

### ***Daily-living behaviours and forgetfulness***

Interventions that focus on reminding patients about their medicines using text messages, electronic reminder devices or alarms showed some short-term promise at improving adherence (Mahtani Kamal et al., 2011, Ryan et al., 2011, Horvath et al., 2012). Here reminder devices were considered in distinct disease groups (namely cardiovascular disease, diabetes and HIV respectively) with Ryan et al. (2011) calling for future work to consider these interventions in patients with multi-morbidity. For example, Vervloet et al. (2012) reviewed interventions based on reminder technologies, which were only able to demonstrate short-term improvements in adherence. This may be because these interventions position adherence as a function of memory, without necessarily taking into consideration the broader elements of how memory is experienced in everyday life.

A key point here is that reminder devices needed to fit into patients' experiences of everyday life in different settings. New technology such as the internet, telehealth, text messaging, videoconferencing, social media and 'smart packaging' (electronic packing, which records when a blister is opened), are favoured by patients as interventions for

improving adherence, with some evidence to support their use (Brath et al., 2013, Harris et al., 2012). Though again these studies report findings with the context of diabetes, which might limit how they can be interpreted in a different disease setting.

### ***Changing medication***

Interventions which are focused on changing medication, through simplifying medication regimens to once daily dosing rather than twice daily or combining medication into one dosage form, has repeatedly improved adherence (Kreyenbuhl et al., 2010, Choudhry et al., 2011, Ryan et al., 2011, Schroeder et al., 2004, Feagan and MacDonald, 2012), although some studies showed no statistical difference in adherence outcomes after frequencies of drug administration were reduced (Barner, 2011, Jamous et al., 2011). Changing the pharmaceutical form, switching from a conventional pill to a disintegrating tablet, can also improve adherence and clinical outcomes (Navarro, 2010). A study found that any change in adherence due to changes in the dosing schedule were likely to be for patients with lower dosing or pill burden to begin with, suggesting once dosing burden is at a certain point, adherence could not be improved (Hauber et al., 2013). Again within this literature, data was collected within highly contextualised settings or abstracted from multiple studies conducted within specific settings. Empirical work is needed that considers these interventions within the context of multiple disease groups.

### ***Complex interventions***

Complex interventions are made up of a number of different interventions such as combining additional counselling at discharge, telemonitoring and videoconferencing with reminder devices and smart packaging. Complex interventions have the most supporting evidence however even here there is contradicting literature with not all investigations into complex interventions showing success in a comprehensive systematic review (Haynes et al., 2008). In the review, complex interventions show the most significant effect on adherence however as the interventions are complex they have a higher cost associated with implementation (Newell et al., 1999, Ryan et al., 2011, Schroeder et al., 2004) and only a minority of these studies reported substantial improvement in adherence. This suggests that the relationship between significant clinical improvements or improvements in patient satisfaction or experience within the context of these complex interventions, may need to be reconsidered in relation to adherence in order to determine future directions for intervention development.

The literature documents intervention development from a range of different yet specific contexts, generating a heterogeneous evidence base that draws on various ontological definitions and conceptual frameworks. Systematic reviews assessing the efficacy of interventions have not demonstrated long-term improvements in adherence. The limited efficacy of these interventions could be due to the heterogeneity of the research methods used to test the interventions or that conceptual models informed by patient-specific, disease-specific or medication-specific evidence have been used to develop interventions from particular perspectives. This identifies a gap in the literature for a novel description of the adherence phenomenon to help direct future intervention development. Furthermore, whilst the literature describes interventions within the context of theoretical frameworks, it does not include evidence of interventions that were located in patients' lived experiences of medicines use – perhaps highlighting a disconnection between experiences of adherence and the development of interventions.

### **Conclusion: An evidence-base framed by biomedicalism**

The literature outlined above has described heterogeneous ontological definitions of the adherence phenomenon underpinned by conflicting evidence concerning reasons for non-adherence and fed by various theoretical framings. It has highlighted the very specific nature of the evidence base that may have limited the application of interventions to improve adherence in different or broader settings. A key inference from the literature is the over-arching normative, biomedical approach to understanding adherence that has systematically dissected the phenomenon, classifying component parts and 'interventionalising' the phenomenon through the construction of normative theories. This approach positions different facilitators and barriers at one end of a schema and 'perfect adherence' at the other, with strategic interventions located as a mediator between the two, as shown in Figure 1 overleaf.



**Figure 1. A biomedical understanding of adherence**

The ‘biomedical approach to’ or ‘biomedical perspective of’ adherence has been used thus far and is used again here to describe the adherence literature. Inspired by the biomedical model of diseases, this perspective describes a trend within the literature to use ordinal measures to dissect and identify modifiable and non-modifiable facilitators and barriers to ‘perfect adherence’. It could be argued that this perspective feeds the ‘interventionalisation’ of the phenomenon, born from the, predominantly, medical and pharmaceutical professions, who might be considered to represent the driving force to understand adherence and develop interventions.

Many of the approaches in the literature were based on positivism, fundamentally underpinned by a search for ‘an ideal truth’ that is ‘out there’ waiting to be uncovered through objective and repeatable methods of investigation. Wilberg (2011) writing about an existential medical model, describes a phenomenon whereby patient experiences are embellished within a pre-supposed description of the experience of illness due to the popular acceptance of the biomedical model. The popularity of this perspective may be due to, as Wilberg also describes, ‘the ability of the paradigm to conceptually separate the patient from the disease’. From this perspective, poor adherence or non-adherence can be, and has been, considered something that is separate from the patient, modifiable, and similar to symptoms of diseases. This separation that Wilberg speaks of is visible in the literature and policy – as outlined earlier, NICE explicitly separates the patient from adherence by positioning adherence as a failing of health service delivery rather than of the patient (National Institute for Health and Clinical Excellence, 2009).

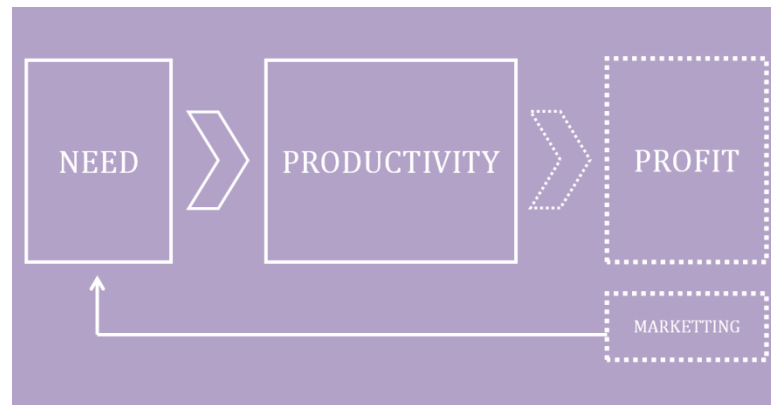
A positivist spectrum of adherence would be paralleled by a health outcomes spectrum, as shown above. Non-adherence is often statistically associated with increased mortality and poorer health outcomes, whilst higher rates of adherence are statistically associated with optimum health outcomes (Simpson et al., 2006). Difficulties arise within this approach to adherence when the model is deconstructed and understood at an ontological level; positivism searches for a single eternal truth posited about an object or concept (Crotty, 1998). For adherence, a posited truth or the 'holy grail' would be perfect adherence. Using numerical values to determine how close someone is to perfect adherence and statistics to determine if this is due to chance or a particular variable, arguably, undermines the human complexities of adherence, as demonstrated by the literature that links ethnicity to adherence, presupposing ethnicity as a function of skin colour.

Whilst there are pockets of work that adopt an approach to understanding adherence from a holistic perspective, the over-arching narrative of the biomedical approach to adherence highlights a gap within the literature for a novel description of adherence, outside of the context of presupposed biomedical beliefs, which might present the experience of adherence from a new perspective.

### **What is missing from the literature?**

An alternative approach might consider adherence behaviours more broadly within the context of day-to-day life across different settings, embodying the experience of adherence in lived reality. In this sense, rather than positing factors, facilitators and barriers, as external to adherence, an alternative approach would see these factors both constructing behaviours to adherence and being constructed by adherence behaviours. The influence of a person's everyday circumstance has on health is well described, 'generally people most susceptible to ill health are those who have the fewest material resources and who are least able to participate fully in everyday life,' (Taylor et al., 2003). Everyday life here is subjectively constructed each day, with metaphorical ups and downs. This lends itself well to the description of illness by Bury (1982) as 'biographical disruption to life'. Patients may be unable to adhere to their prescription as it represents a disruption to their constructed, everyday reality, disrupting yet being part of everyday life. However there is currently no description of patients' experiences, theoretical framework or model that describes taking medicines as prescribed with such an emphasis on interactions of everyday life and how this feeds into subjective, constructed realities of lived experiences across different contexts and settings.

The popularity and familiarity of a 'biomedical approach' to adherence is undermined by activists like Ben Goldacre, author of 'Bad Pharma' (Goldacre, 2012), who argue that the medical and pharmaceutical professions promote positivism and biomedicalism as a vehicle to cultivate and construct a late capitalist model of society and consumption, similar to that described and critiqued by Marx, encompassed by a need and productivity schema, as shown in Figure 3.



**Figure 2. Capitalist model of medicines supply**

Marxist theory describes a constructed social world driven by need; a need for clothing, shelter and food (arguably not entirely constructed, with some underpinning physiological need) leads to investment in the manufacture of products (namely fashionable clothes, shelter, food and pharmaceuticals). Productivity then feeds into cultural and social norms, which in turn fuels need or perceptions of need. Illich describes a phenomenon, social iatrogenesis, that would account for the medicalisation of multiple aspects of life, resulting in the need for pharmaceutical or medical intervention (Illich, 1975). Political and social activists might argue that pharmaceutical industry marketing campaigns manipulate perceptions of need, to increase profit from the sale of the products they manufacture (Goldacre, 2012). Despite political motivations, within this 'approach' patients' perceptions of need are influenced by society and in turn society is constructed by patients' perceptions of need.

Social science and qualitative researchers have used alternative approaches, such as sociological phenomenology, to understand medicines within society; with particular emphasis on the way medicines are constructed as part of patients' lived realities. Much of this work locates medicines as objects of social construction, symbols of illness and embedded with social meaning (Cohen, 2010, Cohen et al., 2012, Cohen et al., 2001, Whyte et al., 2002). From this perspective, patients learn how to interact with medicines within a

defined situation. Whilst these theories have expanded understanding of medicines as social as well as pharmaceutical objects, it is difficult to deduce if their application to adherence has had an impact on the development of adherence interventions or understanding of the adherence phenomenon. For example theories of functionalism (that society is constructed of interdependent structures with particular functions), conflict theory (that people act in response to economic development) and symbolic interaction (that beliefs are constructed through social interaction) do not yet appear to have penetrated the literature as explanatory theories of the adherence phenomenon or in intervention development (Mooney et al., 2007).

Whilst the alternative perspectives of adherence that draw on sociological or phenomenological methods appear to represent a different approach to biomedicalism, much of this work has not penetrated practice, policy or intervention development. Sociological approaches may not be as easy to translate across disciplines, from sociology to biomedical disciplines such as pharmacy, and as such the incomplete uptake of these approaches may have limited understanding of adherence and intervention development.

## **Summary**

The main inferences from this narrative review are constructed of three broad themes that are interpreted from the literature. The first describes issues within the literature that are concerned with the ontology of adherence, i.e. defining adherence through conceptually modelling the phenomenon (see Table 1, Appendix A). The second describes issues concerning the epistemology of adherence, i.e. how adherence can be measured (see Table 2, Appendix A). The third is concerned with the 'interventionalisation' of the phenomenon (see Table 3, Appendix A) whereby the literature is not able to conclusively demonstrate the efficacy of any one intervention to improve long-term adherence, often directing practitioners towards complex, multifaceted and costly interventions. These three themes come together to demonstrate a space in the literature for work that describes the lived experience of the adherence phenomenon, presenting adherence from a novel perspective and delivering new approaches to intervention development.

This narrative review describes and discusses three broad themes that are interpreted from the literature. The first describes issues within the literature that are concerned with the ontology of adherence, i.e. defining adherence through conceptually modelling the phenomenon. The second describes issues concerning theoretical modelling of adherence. The third is concerned with the 'interventionalisation' of the phenomenon, with little

evidence conclusively demonstrating the efficacy of interventions to improve long-term adherence. These three themes describe the adherence literature as located within a 'biomedical perspective' and identifies a space in the literature for work that describes the lived experience of the adherence phenomenon from a novel perspective.

Such a novel description of the adherence phenomenon should be approached from outside of a 'biomedical perspective' or under circumstances where previously held biomedical beliefs and constructs can be set aside, drawing on sociological or phenomenological approaches.

This review has also raised ethical questions concerning adherence research, particularly from a perspective that focuses on the 'interventionalisation' of the phenomenon that has dominated the literature. Whilst this thesis was not dedicated to exploring 'the ethics of adherence', these tensions are discussed in the methods, Appendix C and the final chapter of this thesis draws on these questions to frame future work.

Despite the ethical questions raised by this review, given the poor evidence base for sustainable improvements in adherence using current interventions, a novel description of adherence might also direct future intervention development.

### **Purpose of the study**

The above outlines a perspective of the adherence phenomenon that highlights semantic issues and disparity between theoretical understanding of the phenomenon and the development of demonstrably effective interventions to improve adherence in disease specific silos.

### ***Aim***

To present a novel description of adherence to direct future intervention development

### ***Objectives***

The primary objectives are to a) contribute a novel description to the existing research on medicines adherence by taking a phenomenological approach and b) to provide a framework of findings that contributes to the development of interventions seeking to improve adherence.

### ***Research questions***

- i) What are the lived experiences of medicines adherence of adults taking medication across different disease states (including cardiovascular disease, diabetes mellitus, gout, cancer and chronic obstructive pulmonary disease)?
- ii) What are patients' perspectives of currently available adherence interventions and interventions that are in development?
- iii) Do interventions aiming to improve medicines adherence need to be targeted to different disease groups?

### **Structure of the thesis**

Chapter 3 describes a systematic review and thematic synthesis that engages with the phenomenological literature of adherence, identifying descriptive themes reported in the studies and analytic themes (identity and interaction) that go beyond the studies' original findings. This chapter demonstrates a need for further empirical work to understand patients' experiences of medicines adherence in different disease groups from a phenomenological perspective.

Chapter 4 outlines the epistemology and methodology of the empirical work carried out; describing the underpinning philosophy of phenomenology as well as the practical methods and materials that were used. Chapter 5 outlines the findings of this project briefly before each finding is reported and discussed in detail in subsequent chapters.

Chapter 6 describes patients' construction of personified medicines' identities; outlining patients' lived experiences of getting to know medicines, developing representations of necessity through micro-social interaction with the medicine and establishing micro-social routines that include episodes of short-term non-adherence. This chapter concludes by interpreting and discussing the findings.

Chapter 7 outlines how patients experience adherence through macro-social interaction with wider society, embodied as healthcare professionals, family and friends, the media and policy. This chapter interprets these findings with the findings of Chapter 6, incorporating patients' micro-social interactions with personified medicines' identities within a broader macro-social interaction, to present a novel description of the phenomenon.

Chapter 8 reports patients' perceptions of current interventions, including patients' experiences of educational interventions, multi-compartment compliance aids, reminder devices, peer-support and media as well as the poly pill. This chapter also reports a novel

finding that intervention use is conceptualised by patients as a negative necessity. This chapter interprets these findings and locates interventions within the context of a novel description of adherence, as outlined in Chapter 6 and 7.

Chapter 9 and 10 discuss the findings within the context of current literature, synthesising and interpreting the study findings to answer the research questions. This chapter also highlights the limitations of and reflects on the study, describing the implications of this research and opportunities for future intervention development.

## **Chapter 2: Systematic review and thematic synthesis**

### **Introduction**

Given the conclusions in the previous chapter, it was important to complete a focused review of the literature describing patients' experiences of medicines use from a phenomenological perspective, to consider the phenomenon of adherence a new, i.e. what happens and how it happens, without previously held presuppositions of biomedicalism. A systematic review and thematic synthesis was designed to identify phenomenological literature that described key components of the experience of adherence. This chapter highlights the need for a systematic review of phenomenological literature, describes the methods used to identify relevant titles and conduct thematic synthesis before describing the findings of the review and its implications on further study.

### **Why was a systematic review needed?**

Systematic reviews and meta-analyses are widely accepted by health professionals as a gold-standard approach for pooling data from multiple studies. Formal statistical methods can quantitatively synthesise data from multiple sources in the literature, however where this is inappropriate, as is the case for qualitative data, a thematic or narrative synthesis can be an appropriate approach (Thomas and Harden, 2008). Thematic analysis of phenomenological research was therefore considered as a way to obtain insights into qualitative research concerning patients' lived experiences of medicines adherence and was able to direct the research strategies for adherence interventions based on patient experiences.

As a significant majority of research investigating adherence is conducted within a biomedical paradigm that is mostly quantitative, normative and positivist, an alternative approach to investigating the phenomenon was required to deliver insights, generate new understanding, and direct intervention development.

Qualitative research can therefore provide that alternative approach, although disciplinary conventions, such as journal types and word length, can mean that research findings are not as pervasive in the field as they might be (Pope et al., 2000). Qualitative research provides rich, detailed data about a phenomenon and includes multiple methods of data collection such as semi-structured or unstructured interviews; focus groups; ethnography; and observational studies (Creswell, 2007). Within the qualitative paradigm,

phenomenology is positioned as a method and theoretical framework, based on the philosophical works of Heidegger and Husserl (Moustakas, 1994). The approach, outlined in more detail in the next chapter, considers how objects appear in consciousness as absolute, highlighting the immediacy of consciousness in the construction of reality. The approach has developed over the last century to embody a method of research, which can appear far removed from the scientific biomedical paradigm (Keen, 1975). Phenomenologists argue that phenomena, such as medicines use, are constructed through conscious interaction between subjective humans and the objective physical world. Thus to understand phenomena, researchers must engage with those that have 'lived' through the phenomenon (Moustakas, 1994). Collecting data is concerned with uncovering what others have experienced, through interviews and focus groups – as well as collecting 'grey' data from photography, poetry, and studying other artefacts (Moustakas, 1994). Data can be analysed through interpretative phenomenological analysis, where researchers seek to understand and explain conscious experience, or descriptive transcendental phenomenological reduction, where researchers seek to describe conscious experience, as well as more conventional thematic qualitative analysis, where codes are constructed that describe data (Lopez and Willis, 2004). These methodologies are explained in more detail in the next chapter.

Whilst there are few phenomenological studies in pharmacy, phenomenology has a place within the healthcare research environment (Broekaert et al., 2010) with methods adopted by nurse researchers to add unique insights to the literature (Lopez and Willis, 2004), in areas such as heart failure and HIV, using medical devices to deliver continuous positive airway pressure (CPAP) and specific treatments, for example cholinesterase inhibitors in Alzheimer's disease (Hutchings et al., 2010, Shoukry et al., 2011, Scotto, 2005, Jones, 2002). Phenomenological methods deliver insights into the 'lived experience' of healthcare phenomena of nursing, medical and pharmaceutical interest.

The aim of this chapter is therefore to explore patients' lived experiences of medicines adherence reported in the phenomenological literature, through systematic review and thematic synthesis, to direct future empirical work.

### **Methods for systematic review**

Methodological limitations were assessed following the CASP Qualitative Research Tool and summarised by i) medicines/health issue, ii) methods, iii) sample size, iv) sample

characteristics, and iv) major findings (Glenton et al., 2013). The review protocol was registered with PROSPERO [Registration number CRD42015029494].

The criteria for selecting records for inclusion in the review included studies that i) were a phenomenological investigation ii) were completed with adults iii) were published in a peer-reviewed journal iv) aimed to investigate patients' experiences of medicines adherence. Excluded studies were not published in peer-reviewed journals; were not in adults; did not aim to investigate patients' experience of medicines adherence and were not phenomenological investigations. To maintain consistency and homogeneity, grey literature was not included.

### ***Search strategy and study selection***

A systematic search was performed to identify phenomenological articles that investigated patients' experiences of medicines adherence. CINAHL, PsychInfo, Web of Science, Sociological Abstracts, EMBASE and MEDLINE were searched (details of these searches can be seen in Table 2). Databases were searched individually using the search terms displayed in the table below. Additional records were identified via the snowball method through personal libraries, professional research networks and searching the references of the included records.

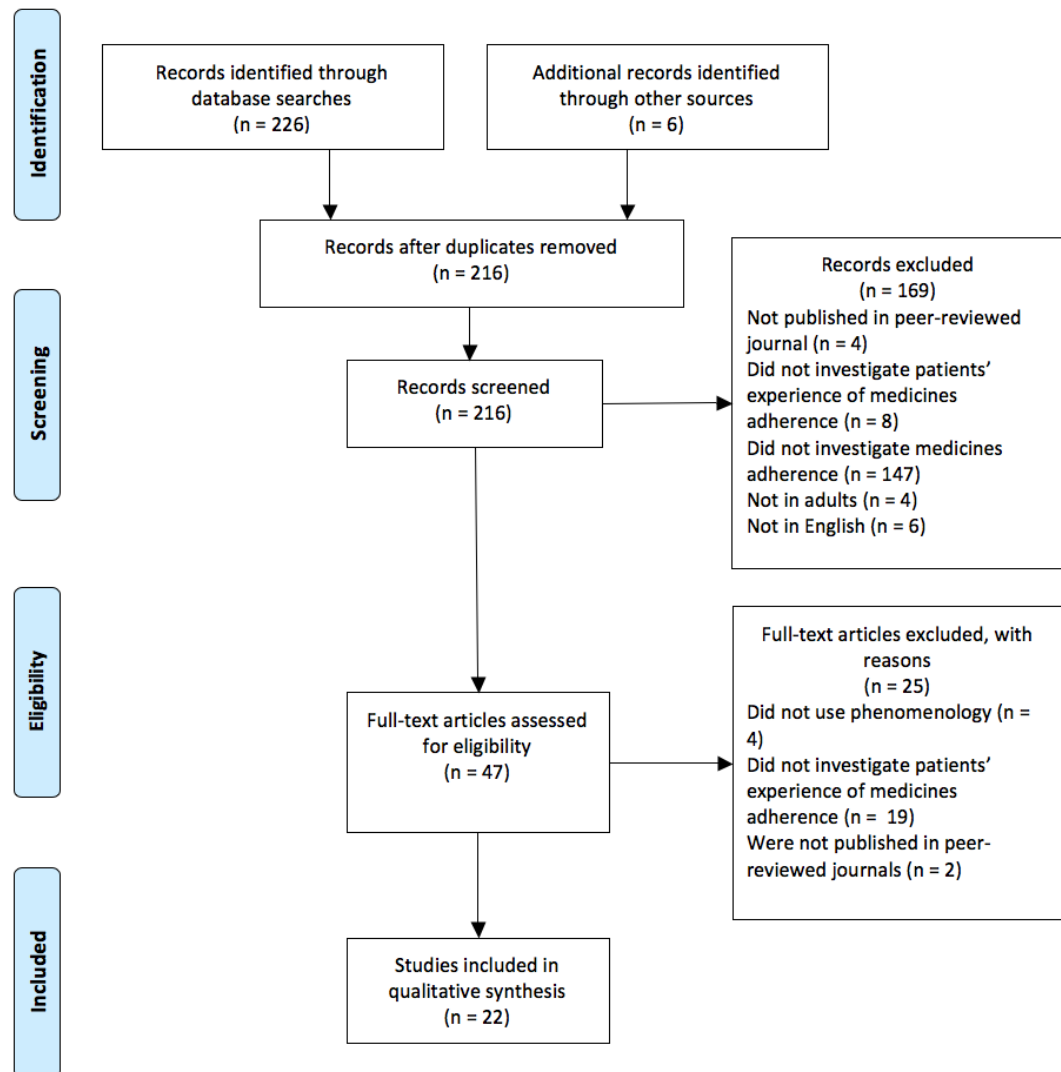
**Table 1. Search Methodology**

Database	Search Terms	Years	Number of Hits	Included
CINAHL	MH 'Medication Compliance' AND phenomenolog*	2002-2014 Academic Journals	33	13
		In English		
MEDLINE	"adherence or concordance or compliance" AND "phenomen*"	1980-2014 [in English, Adult (19 years+)]	126	18
EMBASE	SH "medication compliance" AND "phenomenology or phenomen*"		2	2
PsychInfo	"DE treatment compliance" AND "DE phenomenology"	2009-2014	4	2
Sociological Abstracts Online	"medicines compliance", "medicines concordance", "medicines adherence" and "phenomen*"	1983-2009 [Peer reviewed and in English]	9	3
Web of Science	"medicines adherence", "compliance", "concordance", "phenomenological"	All years	54	5

As "adherence" is a relatively new term to describe medicines-taking behaviour, "concordance" and "compliance" were also used as search terms to identify articles. Database specific subject headings were used to broaden the search to include appropriately indexed subordinate subject headings. To focus the search to phenomenological inquiries "phenomen\*" and "DE phenomenology" were added to the search strategy. Search terms were truncated, such as "phenomen\*", to include phenomenological and phenomenology. The search was limited to articles published in the English language.

Titles and abstracts resulting from the database search were reviewed and full-texts were retrieved for relevant articles or articles that did not provide enough information in the title or abstract. The full-texts of eligible articles were then systematically reviewed for

information about patients' experiences of medicines adherence. Articles that met the inclusion criteria were reviewed in their entirety using the CASP Qualitative Research Tool (Critical Appraisal Skills Programme International Network, 2013). Figure 4 below shows the selection process.



**Figure 3. Systematic review schematic**

### ***Data collection and synthesis***

Thematic analysis was conducted manually and with the use of Nvivo10 computer software [QSR International, Melbourne] according to the method outlined by Thomas and Harden in that data items were considered as all text pertaining to findings, in the abstract, results or findings sections (Thomas and Harden, 2008). Where text in the abstract and discussion related to new concepts, this was also collected for coding. Collected data was coded 'line-by-line' to develop descriptive clusters, which were used to generate analytic themes,

which 'go beyond' the primary studies (Thomas and Harden, 2008). Data was also collected from each study to tabulate i) medicines/health issue, ii) methods, iii) sample size, iv) sample characteristics, and v) major findings as shown in Table 4, Appendix A (Cooke et al., 2012).

Phenomenological and qualitative research is inherently subjective and often perceived as being subject to bias. In phenomenological methodology, researchers are advised to avoid bias through a process of bracketing previously held presuppositions, referred to as epoché, prior to the investigation. Incorporating this with the CASP Tool, bias was assessed based on the documentation of a reflective or epoché by the study authors (Critical Appraisal Skills Programme International Network, 2013). Whilst there is not a principal summary measure, studies' key characteristics and findings are summarised in Table 4, Appendix A. Risk of bias was not assessed formally across the studies and no additional analysis was performed.

## **Findings of the review**

The search strategy identified 47 records of phenomenological investigations into medicines adherence. 25 records did not meet the inclusion criteria (details of these can be seen in Table 5, Appendix A). 22 articles were reviewed in their entirety using the CASP Qualitative Tool and included in a thematic synthesis.

### ***Study characteristics***

The majority of studies were set within the context of HIV (DeMoss et al., 2014, Enriquez et al., 2004, Jones, 2003, Jones, 2002, Mohammadpour et al., 2010, Nguyen et al., 2012, Sidat et al., 2007). Other settings included sickle cell disease (Abadian et al., 2010), asthma (Gamble et al., 2007, Scherman and Löwhagen, 2004), tuberculosis (Naidoo et al., 2009, Tadesse et al., 2013), mental health (including schizophrenia, depression)(Henriksen and Parnas, 2014, Kwinter, 2005, Muir-Cochrane et al., 2006), osteoporosis (Lau et al., 2008, Sale et al., 2011), and diabetes (Tilden et al., 2005). Two studies investigated the experience of adherence in older adults respectively (Sanders and Van Oss, 2013) and in patients with life-long dependency on medicines (De Geest et al., 1994) and who used treatment for headaches (Seng and Holroyd, 2013). Five studies investigated the experience in women only (Hansen et al., 2009, DeMoss et al., 2014, Lau et al., 2008, Nguyen et al., 2012, Tilden et al., 2005) whilst no studies investigated the experience of adherence specifically in men.

Sample sizes varied within the studies included in this review. The lowest sample size was 1, whilst the highest sample size was 149. The median number of participants was 14. In qualitative research, theoretical data saturation often dictates sample size, however phenomenology appeared to offer flexibility concerning appropriate sample sizes and emphasises the depth of analysis (Crotty, 1998). The majority of studies were from the US and Europe although there was a wide range of geographical locations including the UK (Abedian et al., 2010, Gamble et al., 2007), Belgium (De Geest et al., 1994), America (DeMoss et al., 2014, Enriquez et al., 2004, Jones, 2003, Jones, 2002, Kwinter, 2005, Sanders and Van Oss, 2013, Seng and Holroyd, 2013), Denmark (Hansen et al., 2009, Henriksen and Parnas, 2014), Canada (Lau et al., 2008, Sale et al., 2011), Iran (Mohammadpour et al., 2010), Australia (Muir-Cochrane et al., 2006, Sidat et al., 2007, Tilden et al., 2005), South Africa (Naidoo et al., 2009), Vietnam (Nguyen et al., 2012), Sweden (Scherman and Löwhagen, 2004), and Ethiopia (Tadesse et al., 2013).

### **Descriptive themes (results of individual studies)**

The synthesis of results identified four descriptive themes these were i) dislike of medicines, ii) survival, iii) perceived need including two sub-themes of a) symptoms and side-effects and b) cost, and iv) routine.

#### ***Dislike of medicines***

Studies often reported a seemingly pre-predicative dislike for medicines engendered through fear of uncertainty (De Geest et al., 1994, DeMoss et al., 2014, Hansen et al., 2009, Jones, 2002, Jones, 2003, Kwinter, 2005, Muir-Cochrane et al., 2006, Sale et al., 2011, Scherman and Löwhagen, 2004), dependency (Kwinter, 2005, Scherman and Löwhagen, 2004, Seng and Holroyd, 2013) and illicit drug taking (Muir-Cochrane et al., 2006, Mohammadpour et al., 2010, Naidoo et al., 2009). Uncertainty was often described as experiencing a lack of knowledge (Gamble et al., 2007, Hansen et al., 2009, Henriksen and Parnas, 2014, Jones, 2002, Lau et al., 2008, Mohammadpour et al., 2010, Muir-Cochrane et al., 2006, Naidoo et al., 2009, Sale et al., 2011, Seng and Holroyd, 2013) and related to patients accepting the biological causes of their illness (Kwinter, 2005, Scherman and Löwhagen, 2004, Sidat et al., 2007, Tadesse et al., 2013) or adoption of natural or alternative therapies (Hansen et al., 2009, Jones, 2003, Naidoo et al., 2009, Seng and Holroyd, 2013, Tadesse et al., 2013). Participants reported receiving knowledge (Abedian et al., 2010, Lau et al., 2008), obtaining knowledge (Gamble et al., 2007, Jones, 2002) and being 'convinced' to use medicines (Sale et al., 2011, Sidat et al., 2007).

### ***Survival***

Survival, living and a readiness to adhere were reported extensively in the literature (Abedian et al., 2010, DeMoss et al., 2014, Enriquez et al., 2004, Gamble et al., 2007, Jones, 2002, Jones, 2003, Kwinter, 2005, Lau et al., 2008, Mohammadpour et al., 2010, Naidoo et al., 2009, Nguyen et al., 2012, Scherman and Löwhagen, 2004, Sidat et al., 2007, Tadesse et al., 2013). This was described as patients 'choosing to live' and consequently being ready to adhere to treatment (Jones, 2003, Mohammadpour et al., 2010, Sidat et al., 2007). Papers also described adherence as an experience of life-long commitment, highlighting the implications of routine and everyday life on long-term outcomes, such as survival (Jones, 2002, Lau et al., 2008).

### ***Perceived needs***

This theme relates to the frequently stated experience of weighing up the advantages and disadvantages of using a medicine in relation to beliefs about 'need' (Gamble et al., 2007, Hansen et al., 2009, Jones, 2003, Kwinter, 2005, Lau et al., 2008, Mohammadpour et al., 2010, Muir-Cochrane et al., 2006, Scherman and Löwhagen, 2004, Seng and Holroyd, 2013) and was constructed from two sub-themes.

#### ***i) Symptoms and adverse effects***

Studies reported the experience of symptom relief, 'getting better' and the medicines 'doing what it was meant to do'. Papers often recounted a negotiation between the symptoms of a disease and the adverse effects of the medicine (Jones, 2003, Muir-Cochrane et al., 2006, Naidoo et al., 2009, Scherman and Löwhagen, 2004, Seng and Holroyd, 2013, Tadesse et al., 2013). This relates to theme i) dislike of medicines, in that adverse effects were often considered an inevitable part of the experience of adherence.

#### ***ii) Cost***

Six papers reported that the risk benefit analysis included considerations of the cost of the medicine (De Geest et al., 1994, Gamble et al., 2007, Lau et al., 2008, Muir-Cochrane et al., 2006, Seng and Holroyd, 2013, Tadesse et al., 2013). These papers were from a range of health economies, including the UK (Gamble et al., 2007), Europe (De Geest et al., 1994), the USA (Lau et al., 2008, Seng and Holroyd, 2013), Australia (Muir-Cochrane et al., 2006) and Africa (Tadesse et al., 2013). The cost of travel to access the medicine was also conveyed in these studies as central to the experience of adherence in contexts where access to medicines was limited geographically or financially through insurance-based

healthcare models (Tadesse et al., 2013, Seng and Holroyd, 2013, Muir-Cochrane et al., 2006, De Geest et al., 1994).

### ***Routine***

Lifestyle (Abedian et al., 2010, De Geest et al., 1994, DeMoss et al., 2014, Gamble et al., 2007, Jones, 2002, Jones, 2003, Lau et al., 2008, Mohammadpour et al., 2010, Naidoo et al., 2009, Sale et al., 2011, Seng and Holroyd, 2013, Sidat et al., 2007), time (Jones, 2002, Sanders and Van Oss, 2013, Seng and Holroyd, 2013), memory (Broekaert et al., 2010, Hansen et al., 2009, Jones, 2002, Jones, 2003, Keen, 1975, Sale et al., 2011, Thomas and Harden, 2008, Usher et al., 2013), and distraction (De Geest et al., 1994) were found to be components of the experience of an adherence routine. Papers reported task-based activities and the storage of medicines as structural components of the experience (Sanders and Van Oss, 2013, Seng and Holroyd, 2013, Sidat et al., 2007) as well as devices that might be used or prepared as part of the adherence experience (Whyte et al., 2002).

### **Analytic themes**

The descriptive themes were analysed further to construct analytic themes, which attempt to 'go beyond' the findings originally reported in the studies (Thomas and Harden, 2008) and deliver insights into the experiences of a phenomenon that transcend the contexts of the primary research. The analytical themes identified were i) identity and ii) interaction.

### ***Identity***

Pharmaceutical objects were reported to exist within the experience of adherence as embodied actors within a patient's life-world. Medicines were characterised by their efficacy to relieve symptoms and cause adverse effects; were associated with access costs and storage requirements as well as how they should be taken. These identifying features of a medicine represented structural components of the experience and are demonstrated in the quotes below.

*Most patients referred to penicillin as a 'very powerful medication' and this was demonstrated in their accounts that they believe that by taking the penicillin the threat and severity of getting serious infections would be reduced (Abedian et al., 2010)*

*For example, one participant considered his bisphosphonate to be a "minor medication...just more like supplements than medication" (Sale et al., 2011)*

The identity of the medicines also appeared to inform the participant's identity, as below,

*And I think when Prozac came out somehow the brand name...I think Prozac became synonymous with crazy. For a lot of people. And so, people would say, "oh well, they're on Prozac (Kwinter, 2005)*

As informed by the identity of the medicine, the identity of the patient emerged as part of the experience of adherence as noted in this quote,

*Many participants expressed feelings, such as loss of identity, loss of roles within personal relationships and embarrassment in relation to their steroid treatment. Loss of identity included issues such as personality changes, feelings of 'not being themselves', being unable to fulfil their normal role within the family unit, or being perceived as different by friends or family.(Gamble et al., 2007)*

Patient's identity and personal values influenced adherence as they constructed ideals of right and wrong and how to live a perceived healthy life.

*These young women were determined to pursue a healthy lifestyle and considered medicine use to directly conflict with their health-related values. One informant felt it was "wrong" to take medicine, and shared her holistic view of healthy living: "If you do the things, if you are healthy in your daily life, if you are less stressed out and stuff, then that makes it so that you have less of a need for medicine. Um. So I really try to avoid medicine, in every way".(Hansen et al., 2009)*

A dislike of medicines as part of the patient's identity was renegotiated by perceptions of need, ultimately leading to the modification of the patient's identity, who they are, what they are and their ability to survive. This dislike of medicines is internalised and becomes a key part of patients' identity.

*You know, I have been on medication now for 8 years and it's [sic] such a part of my life and the knowledge, the simple knowledge that if I had not taken my pills I would've been dead by now is enough to keep me taking the pills. I am healthy as anything. I'd probably never been as healthy as I am right now but I've and I assume I'd be dead so... (Sidat et al., 2007)*

In being prescribed a medicine to which they are expected to adhere, patients' perceived need for the medicine means they often redefined their dislike of medicine and alter a key part of their identity in order to use medicines and survive.

Identities of patients and of medicines appeared to be constructed through interaction with each other and wider social actors.

### ***Interaction***

Participants constructed identities through interaction with their medicines; with healthcare professionals; with family members; the disease and with 'healthcare literature' (for example blood results and hospital charts).

*In-depth research by participants paralleled the search for the 'right' health care provider and the 'right' HIV medication, and included activities such as reading magazines, looking for information about HIV treatment on the Internet, attending community HIV-related groups and listening to lectures about HIV disease(Enriquez et al., 2004)*

*The metaphor that emerged from the data was Life in a Pill Bottle, which reflected the central focus of HAART in participants' lives and describes the complex relationships that evolve between the person, the medications and the virus.(Jones, 2003)*

These interactions formed such a significant part of the experience of adherence, they often resulted in changes to the perceived identity of the medicine, particularly in relation to how it should be taken, which occasionally led to non-adherence, as demonstrated by the quote below,

*When I got out of the hospital, he (health care provider) was really giving up on me. I thought, 'Well, this is not the person I want caring for me'. I decided, well, I want to live so I need to find a new doctor, which I did. "I took them (the HIV medications) about two months and stopped because I did not like him (health care provider)."(Enriquez et al., 2004)*

Interaction between patients' experience of symptom relief, adverse effects and their healthcare professional is demonstrated further in this quote, here the patient clearly modifies their medicines-taking to align with their beliefs about steroids,

*I would be on my knees rather than take them, as time goes on and how I feel within myself, if I feel that I'm starting to come round. I will cut them down and maybe the consultant has said stay on two tablets until I see you in four weeks, but if I feel okay I won't stay on those two, I mean I probably will cut them down again, maybe I shouldn't but...(Gamble et al., 2007)*

Interaction with expert healthcare professionals tried to facilitate the construction of knowledge relating to the identity of the medicine, the disease and the patient that was congruent with predominant medical beliefs, consequently informing beliefs about 'need'. This was not always successful, and led to contention between predominant medical knowledge and the patients' own knowledge base, as demonstrated in the quote below,

*"so then I started to feel better and I started actually to get involved in more self-help kinds of things and reading stuff that was critical of most of what I had experienced in the mental health system. They really try to convince you that the illnesses that you have are biological and that if you take the drugs and do what we think you need to do, then you'll be okay.",(Kwinter, 2005)*

The construction of knowledge through interaction was often described as 'convincing' or 'being convinced' and related to the identity of the medicine including it's perceived need to be taken, and the patient's identity and in relation to how they should use medicines. This is demonstrated below,

*"[the GP] that she automatically put women on bone density medication once they were fifty or over...So I was not convinced to take it because...I wasn't convinced that I needed it. Not at all." She was then referred to a specialist who gave her an in-depth explanation of her condition and about the medication itself. Following the visit with her specialist, this participant decided to take osteoporosis medication: "I felt very confident and secure once I spoke with her [the specialist] in detail about my concerns taking the drug. I just didn't want to take any drug unless it was necessary. But she explained everything so thoroughly and had information to back it up from my charts. So she convinced me and she said she doesn't mainly prescribe drugs either, nor does she like taking them herself unless it's necessary." (Sale et al., 2011)*

The above quote demonstrates the interaction between identities of the patient and of the medication.

## **Implications**

The findings from this synthesis suggest that a component of the experience of adherence is the interaction between the distinct, textual identities of social actors. Adherence is reported as an experience of dynamic routine, informed by knowledge about the patient and about medicines that is gained from wider society. The analytic themes of identity and interaction appear to embody the descriptive themes, whereby disliking medicines and being driven to survive are enacted as part of a patient's identity and the perceived need of a medicine constitute the medicine's identity as a tacit social actor, that relieves symptoms, causes side effects and costs money. Experiences of routine appear to represent interaction between the patient's identity and the medicine's identity. The phenomenological literature then describes the structural 'essence' of adherence as identity, of patients and medicines, and as interaction between the patient, their medicine and wider social interaction with friends, family, and health professionals. Knowledge and perceptions, constructed from social interaction, are reported to enable patients to modify medicines-taking beliefs and practices. Interactions with healthcare professionals were reported to focus on 'convincing' patients of the need for medicines, which was at odds with interactions with family, friends, and the media.

This work supports that conducted using other approaches, which identified the importance of perceived need (Horne et al., 2013). Horne et al. argue that internal negotiations between the patient's perceived need of a medicine and the patient's concerns about adverse effects position adherence as a dichotomy. This was also seen in the reviewed phenomenological literature, as perceptions of need and of survival were explicitly described in relation to medicines taking within the context of symptoms and side effects. The construction of knowledge about the safety and efficacy of medicines, and hence the need of medicines, is also supported by other work, which identified construction of lay pharmacological beliefs (Webster et al., 2009). Conceptualising medicines as social entities, as well as biochemical ones, is described in literature outside the scope of this review (Whyte et al., 2002, Cohen et al., 2001, Anderson and Roy, 2013). Particularly the work by Dingwall and Wilson, which reported the 'symbolic transformation' pharmacists perform when dispensing medicines, changing medicines from biochemical to social entities (Dingwall and Wilson, 1995) frames interactional relationships as significant

parts of the adherence experience is also supported by other work (Chai et al., 2014, Laba et al.). This highlights the importance of initial support and reinforcement when medicines are first prescribed and crucially, throughout the life of the patient and the prescription product.

### ***Limitations of this review***

Synthesis of qualitative data is often controversial as qualitative findings are deeply contextualised and so difficult to transfer from one setting to another. Thomas and Harden argue that 'the act of synthesis could be viewed as similar to the role of a research user when reading a piece of qualitative research and deciding how useful it is to their own situation.' (Thomas and Harden, 2008). They go on to argue that context can be preserved if aims, methods, sample characteristics and settings of the manuscripts synthesis are shared as part of the synthesis, as in Table 4, Appendix A. Phenomenologists are encouraged to present their findings in creative and novel ways to engage wider public interest. Due to the varied nature of phenomenological research, it is possible some studies were not identified, such as those presented as art or poetry and not published in journals. As there is no standardised method for identifying or assessing the quality of this type of publication systematically, these works could not be included in this review or thematic synthesis.

Whilst the findings support the use of phenomenology as a theoretical framework and method to investigate adherence, a further limitation of this review is that it only included studies that explicitly aimed to investigate the experience of medicines adherence. This meant that studies investigating only a part of the experience of medicines adherence, for example investigating beliefs about treatment, or studies investigating the broader experience of healthcare, such as self-management of diabetes, were excluded from the study. It could be argued that these excluded papers may have included relevant extracts however as their primary aim was not investigating the experience of adherence *per se*, these extracts may have been hard to identify or contentious in their relevance to adherence.

### **Conclusion**

In relation to this thesis, this review has considered the literature by focusing on patients' lived experiences of adherence. Identifying an interaction between identity of the patient and the identity of the medicine within very specific, lived, experiences. One of the

drawbacks of this literature is that the majority of studies were conducted within specific disease contexts. This highlights a gap in the literature that describes patients' experiences of adherence across disease contexts.

Of particular pertinence is the delineation of disease symptomology and how this constructs patients' experiences of adherence. The literature, both outlined in Chapter 2 and above, suggests that symptoms, and other somatic experiences such as side effects, play a key part in a risk benefit analysis that constructs perceptions of necessity, both as part of a patient's identity, but also a medicine's identity. However the literature does not adequately describe patients' experiences of adherence across disease contexts that have varied symptom profiles. For example patients with gout and COPD experience symptoms of pain and breathlessness, where as patients with cardiovascular disease and diabetes might not experience symptoms. Indeed somatic experiences of side effects in some contexts can appear to be more detrimental than disease symptoms, such as patients with cancer. Understanding patients' experience within the context of multiple disease states that embody varied symptom profiles would enable in-depth understanding of the adherence phenomenon. Disease areas that have high prevalence and have different symptomatic profiles, such as gout, COPD, cardiovascular disease, diabetes and cancer would ensure the inclusion of varied experiences across disease groups.

Within the literature, the experience of symptoms, and arguably symptom relief, represents an interaction between the patient and their medication. This highlights an important area for future intervention development. However there is little in the way of evidence that directs future intervention development be aimed toward patients within specific or different disease contexts, i.e. that future interventions be directed to utilise patients' interaction with symptoms to improve adherence. Indeed that much of the literature is conducted within disease-specific silos might limit the transferability of the study findings to intervention development, where interventions might be directed towards patients with different disease contexts or comorbidities. Further understanding is therefore needed that locates adherence intervention development within the experience of adherence across different disease groups.

These considerations present three questions;

- i) What are the lived experiences of medicines adherence in adults taking medication across different disease states (including cardiovascular disease, diabetes mellitus, gout, cancer and chronic obstructive pulmonary disease)?
- ii) What are patients' perspective of currently available adherence interventions and interventions that are in development?
- iii) Do interventions aiming to improve medicines non-adherence need to be targeted to different disease groups?

The next chapter of this thesis outlines the conceptual framework, methodology and methods used to answer these questions.

## **Chapter 3: Epistemology, methodology, and methods**

The previous chapter justified the need for a study that investigates patients' lived experiences of medicines adherence in different disease contexts. This chapter describes the methods and materials used to carry out the study, as well as the principles of credibility, transferability, dependability and confirmability. In a sense, this chapter carefully considers 'what was done' and 'why it was done'.

### **Epistemology: The nature of knowledge**

Much of the research that has investigated adherence uses different methodology and arguments can be made (and has been made in an earlier chapter) about the appropriateness of those methodologies when investigating such a complex human phenomenon. Methodologies might be argued to be manifestations of epistemological and ontological positions and, for this study, the epistemological position of the approach informed the methods used.

Philosophy is fundamentally integral to scientific disciplines (Crotty, 1998), however philosophy as a discipline has retreated back from the foreground of research and the practical application of philosophy can be hidden from view by the focus on a plethora of methods, methodologies and theoretical frameworks. More recently philosophy has been tied to the likes of theology and consequently, empirical natural scientists find philosophical inquiry obfuscated and erroneous. Ferguson describes philosophy as a 'meta-science'; encompassing all scientific practices and research based on reason, and therefore doubt (Ferguson, 2006, Berger, 1963). Doubt in turn can be considered to link all scientific practices to philosophical inquiry.

As outlined in the previous chapters, the majority of adherence research is approached from a normative perspective - although pharmacy research from different perspectives is growing. One truth, posited by an object and only revealed through the scientific method of experimentation, repetition and validation is how pharmacists typically understand the world. What knowledge 'is' for a healthcare professional in a positivist paradigm then, is concentrated on prediction and certainty; confidence intervals and probability coefficients all aim to objectify experiences to better 'know' what will happen in the future; predicting survival based on certain behaviours, for example.

The concept that there is more than one theory of knowledge can be quite jarring. Exploring different paradigms in an attempt to understand reality, and the way things 'are' (known as ontology) and exploring how what is known is known (epistemology) are areas that are very rarely discussed, taught or considered in the majority of healthcare settings or health education – although this appears to be increasing. Granted healthcare professionals may be too busy doing the day job, ontology and epistemology are areas that can dramatically alter the way research outcomes are understood and applied in clinical practice. A constructivist epistemology (as opposed to a positivist one) argues that meaning and knowledge are built through the subjective conscious perception of objective characteristics. A solid dosage form, such as a tablet, has objective properties, for example its colour, size, shape, and excipients, however tablets also have subjectively-perceived properties, including the social constructs of the tablet, i.e. a remedy, a choking hazard, an inconvenience. The social constructs of an object only exist when they are perceived through subjective consciousness and these constructs can only be accessed through conscious experiences. Ferguson (2006) describes consciousness as 'not a picture of an absent world contained within the mind of an individual, it *is* the world' (page 26), thus to study a phenomenon, such as medicines adherence, experiential data based on subjective perceptions of objective characteristics can be argued to be of paramount importance.

Perceptions and experiences are rich, detailed and comprehensive. Traditional approaches in adherence research to capture experiences have, being framed by biomedical perspectives, predominantly used surveys or questionnaires to collect data. This allows statistical analysis to be conducted to identify any significant differences between experiences of adherence and to categorise variables that might mediate the experience. These approaches are often argued to be unable to capture the complexity of conscious experience (Moustakas, 1994, Crotty, 1998) and as such a qualitative approach must be considered. When investigating patients' experiences qualitative research uses methods such as interviews, focus groups and observations to collect rich data pertaining to phenomenon and are often considered more appropriate to uncover the dynamic complexity of human experiences (Creswell, 2007). Many different forms of qualitative enquiry have been developed, with each purporting advantages and disadvantages to others. Grounded theory, narrative approach, phenomenology and ethnography are reputable and rigorous methods that could be used to study patients' real-world experiences of adherence.

Deciding which qualitative research approach to use can be difficult. Philosophical, conceptual or theoretical frameworks or ideologies often underpin each approach. Aligning the aim of the research with the underpinning ontological, epistemological and theoretical perspective allows a theoretically congruent research approach to be adopted. As outlined in the previous chapters, medicines adherence can be defined and described using a plethora of conflicting conceptual or theoretical frameworks and so aligning one of these to a qualitative method presented somewhat of a challenge, as epistemologically it meant giving predominance to one 'way of thinking' about adherence. A narrative approach might elucidate an in-depth story of medicines taking and require collecting field notes and artefacts which would be difficult to do with a patient's medicines - taking an artefact like empty medication packaging would reveal a participant's identity, exposing a study risk of compromising participant confidentiality, unless it was defaced to remove confidential information, which would arguably decrease the integrity of the artefacts, and the study. Additionally, a narrative approach often details quite abstract concepts, which future readers might struggle with, if the outcomes of this research are going to influence practitioners and policy, they need to be translatable and easily understandable. Finally within a narrative approach, researchers subjectively reconstruct a phenomenon, potentially devaluing the chemical nature of medicines and the objective reality of medicines use.

An ethnography, which includes observation of culture-sharing groups, would not be appropriate as identifying a culture-sharing group within disease states would be exceptionally difficult - just because two people share an illness does not infer they share a culture, indeed medicines taking appears across cultural groups and an ethnography would arguably discover more about other structures of culture than about medicines taking. Ethnography would elicit patients' experiences of medicines use however this would require a substantial amount of time in the field and would make the practicalities of development expected during doctoral study difficult. For these practical reasons, an ethnographic approach was not chosen as the method of enquiry.

Grounded theory attempts to produce a novel theory, interpreting the experience of the phenomenon to generate an explanatory model. Phenomenology, as an alternative approach, seeks to produce a novel description of the experience, as such, which would be constructed from the data by forcing the research team to identify and reject presuppositions and prejudices about a phenomenon through a process known as epoché.

Grounded theory and phenomenology could both have been used as appropriate methods to investigate experiences of medicine use within the context of different disease groups, as they both involve an element of basing findings in data rather than presupposed views. A grounded theory study would produce a model of the process of taking medicines and inferences could be made about differences between the models – trying to explain why patients in different groups might have different experiences. Conversely a phenomenology, whilst still adhering to many of the philosophical principles of grounded theory, i.e. trying to limit the influence of the researchers prior knowledge on the outcome of the research, would produce textural and structural descriptions of ‘what’ happens and ‘how’ it happens when participants are taking medicines for their disease.

Moustakas (1994) describes applying phenomenological methods to human sciences research by describing five characteristics of the methodology. The first is that phenomenology considers the whole nature of a phenomenon, free from preconceived biases from the natural sciences, and constructs an understanding based on what is given in the data. Concepts, judgments and understanding are developed through reflection and intuition to, without producing processes, models or explanations, describing what and how the phenomenon of inquiry occurs. Finally, phenomenology is intent on the interaction between the objective and subjective, allowing for a researcher to consider multiple aspects of the phenomenon from an almost pluralist perspective, without rigidly observing positivist or constructivist practices. After reading an extract of the phenomenology of time (Moustakas, 1994), it appeared that to adopt a phenomenological approach would produce a description that, after it having been read, a reader would understand the phenomenon more clearly.

In contrast, Stern and Porr (2011) said that the four fundamental principles of grounded theory were ‘explanation never description’ whilst Moustakas describes phenomenology as providing a way to ‘understand something better’ (van Manen, 2011, Moustakas, 1994). After reviewing the literature, another theory would not contribute significantly to practice or research. However a phenomenology, which would provide a novel description of the phenomenon, to help practitioners, policy makers, and academics, ‘understand adherence better’, would make a novel contribution to the literature. A description of adherence, that is not trying to explain the process, but enhance our understanding of the experience of adherence, would be additionally useful if it were to direct intervention development. As a

result, phenomenology was chosen as the methodological and conceptual underpinning for this work. The conceptual background to phenomenology is outlined in more detail below.

## **Phenomenology**

Phenomenology is a methodology used to explore experiences, described by Ferguson (2006) as 'a philosophical movement combining rigorous science and mystical theology'. Phenomenology speaks to the importance of experience and experience that has been lived through. Husserl, a German philosopher who established a school of phenomenology, broke with positivist, natural science epistemology, stating 'naturalists and historicists misinterpret ideas as facts... transform all reality, all life, into an incomprehensible, idealess confusion of *facts*. The superstition of the *fact* is common to them all' (Ferguson, 2006). This quote essentially describes a constant doubt and casts a shadow on the elements of 'certainty' that have come to be expected from 'scientific' research when translated into practice or policy. Phenomenology then represents both a method of investigation and a conceptual framework.

Constructivism argues that meaning and knowledge are built through the subjective conscious perception of objective characteristics. This paradigm or perspective lends itself well to phenomenology's concept of intentionality. The subjective consciousness intends towards the objective characteristics to construct reality and experience (Ferguson, 2006), in other words, we think subjectively about objective things. The resulting subjective processes of conscious perception (that is knowing, judging, remembering, desiring) are intended towards the objectivity of the object (that is its size, shape, colour). The resultant consciousness is constructed from two sources; the subjective perception and the objective characteristic; this process constructs reality and experience (Moustakas, 1994). This description from Moustakas highlights the key role that phenomenology has for investigating adherence. Each medication will have objective, reproducible and predictable characteristics posited about its nature; a tablet might be blue, angular and hard where as a liquid may be bright pink, sticky and sweet. Those physical, chemical characteristics are unlikely to change from patient to patient. Within a phenomenological approach, the objective characteristics are interpreted and processed subjectively by each patient, obtaining meaning, influence and importance from a subjective perspective. In that sense, whilst medication maybe be objectively manufactured to have certain characteristics, patients might experience them differently, such as disliking the sweet taste. Experience

then is made up of the dynamic negotiation between internal psycho-social processes and external objective stimulus.

### ***Interpretation and description***

Multiple schools of practice exist within the phenomenological discipline. For the purpose of this thesis, two phenomenological practices are outlined. The first represents interpretive phenomenology, also known as hermeneutic phenomenology, which focuses on the interpretation of experience as consciousness and more readily accepts that any research represents the interpretations of the researcher (Moustakas, 1994, van Manen, 2011).

Alternatively transcendental phenomenology is focused on the description of phenomenon from constitutive parts, the 'what happens' and 'how it happens' of experiences that construct consciousness. Whilst critics argue that all experience is interpreted through language (Gadamer, 1976) the transcendental phenomenological approach is argued to be more 'scientific' or 'robust' (Giorgi, 1997), as it provides a mechanism to recognise and address biases brought to research by the researcher (the epoché). As this study set out to provide an alternative description of adherence, transcendental phenomenology, as oppose to interpretive phenomenology, was adopted as the methodological framework that would underpin the study.

### ***Textural and structural descriptions***

A textural description of reality or experience was expected to include all aspects of the phenomenon, with 'outliers' brought forward for discussion and reflection to allow each dimension of the phenomenon to be given equal attention. Describing each aspect of adherence from many view points, collected through qualitative in-depth semi-structured interviews, until a "sense of fulfilment" (page 78) is achieved was needed to generate a detailed, comprehensive description of adherence (Stern and Porr, 2011, Moustakas, 1994). After describing the texture of a phenomenon, i.e. what happens, the analysis turns to reflecting the structural components that precipitated the phenomenon, that is 'how it happened'. This was vocalised by participants, as feelings, thoughts and experiences constructed by conscious acts of thinking, judging, imagining and recollecting. Although the two constructs are described as different 'phases' of research, Keen (1975) advises that structures and textures of experiences are interlocking and consequently a phenomenological investigation is fluid and moves from structural to textural and *vice*

*versa* (Moustakas, 1994, Keen, 1975). Figure 4 demonstrates the actual steps taken during a transcendental phenomenological analysis.



**Figure 4. Process of transcendental phenomenology**

Based on the Vancouver School of Doing Phenomenology (Keen, 1975), the method can be fragmented into three identifiable stages; epoché, transcendental reduction and imaginative variation. Transcendental reduction focuses on the construction of codes, units of meanings or nodes to demonstrate the textural aspects of the phenomenon, whilst imaginative variation uses the researchers imagination to see connections between the structural aspects of the phenomenon that precipitate the textural aspects. Through this process of transcendental reduction and imaginative variation, the value of the data is highlighted, that data, as such, pertains only to ideas and it is ideas that are powerful, useful tools. For example, observing, experiencing and demonstrating that the colour ‘red’ exists only then describes an idea of ‘redness’; the idea is then toyed and played with conceptually to develop innovations of redness and it is this that consequently produces impact and deeper understanding. Conventional thematic analysis using coding software can be conducted during the two later stages to identify textural aspects (what happened) and the structural aspects (how it happened). A transcendental phenomenology identifying structures of multiple experiences, which transcend the contextual boundaries of those experiences was designed.

Banton (2005) highlights that social research is influenced by the researcher’s personal traits and characteristics, with objectivity in the social sciences only achieved through interaction with other researchers. Interacting with other researchers can be reflective in nature; drawing on the experiences of different researchers, however Moustakas (1994) describes this as a difficulty of transcendentalism, ‘the challenge is to silence the directing voices and sounds, internally and externally, to remove from myself manipulating or

predisposing influences and to become completely and solely attuned to just what appears, to the encounter the phenomenon, as such' (page 88). Moustakas also describes a seclusion and withdrawal of the phenomenologist during the research process of epoché, reduction and imaginative variation from the research environment to avoid adopting the biases, prejudices and presuppositions of those around him. He describes the influences of fellow researchers as something that may not be completely transcended, which might still be identified by the epoché, but might not be able to be rejected. Moustakas offers some hope in that with careful, intensive, and reflective epoché, the prejudices and pre-conception of others can be faithfully revealed as such, and consequently be identified and analysis scrutinised.

### ***Bracketing***

Bracketing in phenomenology involves reflecting and rejecting any pre-existing or pre-conceived ideas about a phenomenon; setting aside judgments about the natural world to enable the essential essence of a phenomenon to be understood. Transcending the physical and natural world, as healthcare professionals, can be difficult as the physical sciences are the territories that most health professionals are educated and practice in. For a pharmacist, the early years of education are built on a foundation of natural science. Coming to phenomenology as a pharmacist was refreshing; the epistemological and ontological changes required were very different to the quantitative paradigm of traditional chemistry, biology and physics. Epoché, to reduce pre-conceived biases, is a reflective and continuous process. In this respect, transcendental phenomenology not only tries to find the transcendental nature of the phenomenon, but also supports the researcher to transcend their previously held presuppositions and *a priori* knowledge.

A view could be taken that it is impossible to completely transcend the natural sciences or sociolinguistic knowledge and as a result they mar all phenomenological investigations. Even if a complete sense of epoché cannot be achieved, a pharmacist-researcher, or any researcher, might still benefit by identifying biases and 'opening up' to the idea of a different perceived reality (Creswell, 2007, Moustakas, 1994). Bracketing out or identifying preconceived understanding of an experience prior to thematic coding, enabled reflexive anticipation of theme emergence, i.e. are these themes being identified due to previously held beliefs or are they in the data? Can this data be considered in a different way? Continuing this process through repeated epoché establishes if themes or codes are emerging due to pre-conceived ideas or due to the data. An example of how this could play

out during analysis is that, as a pharmacist prior knowledge about pharmacokinetics, pharmacodynamics and unwanted adverse effects, might have biased the coding such that adverse effects, pharmacodynamics and pharmacokinetic issues are identified predominantly. Epoché allowed codes to be critiqued and reflectively scrutinised against the transcripts for the presence of the code with repeated, informal epoché conducted at regular intervals to reduce biases generated from coding previous data. In essence then, bracketing and epoché acknowledges biases and attempts to circumvent them.

An undated essay by Boghossian of New York University (Boghossian, Undated) draws on sociological constructivism and the sociology of knowledge; arguing that knowledge is subject to social forces (ideas, beliefs) and discusses Kant's philosophy of transcendental idealism. Kant's philosophy, resembling Plato's shadow philosophy, proposes that there is a world that exists independently of the human mind and only when humans think, speak or remember to make sense of the world, that it is constructed. As humans make sense of the world it is constructed socially around them, demonstrated in that humans from different social groups make sense of the world differently, the philosophy argues that the world that is known is socially constructed. This is not too dissimilar to the fundamental ideology of phenomenology. Transcending the known world through reflexive reduction allows experiences to be seen for what they are, without being marred by preconceived ideas of truth or knowledge, better illuminating 'the absolute' (Moustakas, 1994).

Husserl, was a German philosopher who wrote about the ontology, epistemology and philosophy of phenomenology and Moustakas quotes Husserl, "all scientific knowledge, rests on inner evidence" (page 26), in this quote, Husserl is describing knowledge as the culmination of inner reflections of scientists and draws together qualitative and quantitative researchers. This further builds on the work of Descartes' philosophy of reality, where by all reality is subjectively perceived about an object. Perceptions of reality are constructed through a process Kockelman called 'ideation'. In ideation, empirical experiences are transformed into essential insights, creating meaning. Indeed, understanding 'meaning making' through a philosophical lens underpinned the development of an understanding of epistemology, how what is known, is known. Philosophising and theorising about the nature of knowledge and reality presented itself almost accidentally when bracketing. The philosophies of metaphysics (monism, atomism, pythagoreanism) to more cultural and ethical philosophies, like Protagoras' relativism, helped to understand that 'the scientific method' as a combination of age old philosophies

of reasoning (Parmenides, c515-445 BC), questioning (Socrates, 469-399 BC) and empiricism (Aristotle, 384-322 BC) meant that philosophy, formerly considered a 'wooly' discipline was actually an integral part of understanding the world that had perhaps been overshadowed by biomedicalism. Therefore to understand what was already known about the world, understanding the philosophical position was appropriate and an essential part of the epoché. Through epoché knowledge of the world that is constructed on presuppositions, prejudices and *a priori* knowledge can be identified and rejected.

Epoché or 'bracketing out' of preconceived ideas about medicines adherence can be found in Appendix A. The text is presented in the first person and is included to demonstrate the adoption of the epoché process within the study. The text was used during the analysis to scrutinise the codes produced and provides an insight, and summary, of *a priori* opinions and beliefs about medicines adherence. Epoché was practised informally prior to interviews, focus groups and analysis and was regularly referred to throughout the analysis to recognise themes that may have been projected onto the data based on previously held beliefs.

The extract represents views of adherence that might be described as typical for practising clinical pharmacists. Identifying these beliefs, views and values enabled them to be rejected or bracketed and research approached with a more open mind. This thesis now describes the methods and materials of the study.

### **Reflexivity**

Using the approach outlined above was not without contention. Whilst theoretical epoché may be achieved to enable rigorous knowledge creation by a social scientist, the ethico-legal responsibilities of a healthcare professional conducting social science research may not. As a pharmacist, upon disclosure of episodes of non-adherence, General Pharmaceutical Council standards dictate that the pharmacist must intervene. However, as a social scientist, researching non-adherence, intervention during research interviews obfuscates the nature of interview, to observe, elicit, listen. The dual identity of pharmacist and researcher investigating medicines adherence presented several issues, which were documented and worked through in Appendix C, the ethics of studying adherence.

### ***The role of the funder and theoretical positioning***

This research was funded by a joint grant from Durham University (60%) and AstraZeneca (40%). AstraZeneca acted in an advisory capacity preserving academic rigour, oversight,

freedom and independence. That AstraZeneca funded this work represents a theoretical juxtaposition. Thus far this work has recognised an over-arching biomedical approach that has driven adherence intervention development. Whilst this thesis is contributing to the process of interventionalisation, by investigating the phenomenon with a view to direct future intervention development, a critical reflection of this work can be made as to the paradigmatic alignment between describing patients' experiences of adherence using social research methodology and underpinning drivers to develop interventions that manipulate that experience. Directing future intervention development is congruent with a positivist, biomedical approach to adherence that is located within a paternalistic relationship between the patient, their medication, healthcare providers and the industry. Whilst the work that directs intervention development in this thesis is posited within a phenomenological and sociological sphere, which is underpinned by a rejection of biomedicalism and by extension the need for intervention development. At this juxtaposition, a pluralistic perspective is needed that enables the two paradigms of positivism and constructivism to exist simultaneously, side-by-side, such that whilst the outcomes of medicines adherence can be physicochemical the experiences can be social. Returning to the notion that 'medicines do not work in patients that do not take them', the physical impact of medicines misuse through non-adherence has an impact on health outcomes and experiences of everyday life that exist beyond physicochemical boundaries, as sociological, psychological, spiritual and meta-physical phenomenon. It is in this spirit that this research is pursued.

## **Methods and materials**

The sampling and recruitment strategies used for the study are outlined below and include the population studied, the inclusion and exclusion criteria, and the details of the pharmacies and the general practices that were involved in the recruitment.

### ***Sampling and recruitment***

Pharmacists and general practitioners (described below) identified participants with one of the following conditions; cardiovascular disease, COPD, gout, cancer or diabetes mellitus. These disease groups were chosen based on symptomatic profiles, as cardiovascular disease and diabetes mellitus type two are mainly asymptomatic diseases, which patients can be unaware of until diagnosis, whereas chronic obstructive pulmonary disease and gout are two diseases which have clear symptoms, that patients are acutely aware of, such as breathlessness and pain, respectively. Finally patients with cancer often have to take

medication that can give them worse side effects than the symptoms of the disease, presenting an area that was expected to offer a different experience of medicines adherence. These disease areas were chosen with input from the supervisory team at Durham University, the advisory team at AstraZeneca and the Division of Pharmacy Patient and Public Involvement Group as well as being based on my own clinical experience and knowledge gained from my familiarisation with the literature. A decision to limit the study to these diseases (rather than include additional disease contexts that represent different symptomatic profiles such as depression or anxiety) was based on the practicalities of research and ensuring the project was achievable. In instances of co-morbidity, participants were asked to identify which disease group they perceived to be their primary diagnosis or main concern. This allowed the research to be framed in patients' perceived realities. For example, a patient may have hypertension, diabetes and gout however perceive their main condition to be diabetes, and so they would be recruited into the diabetes group. In a situation when participants discuss how they use their medicines in a relational context, this data added to the depth of the research and transcendental understanding of the contextual use of medicines in that population.

Originally the study aimed to recruit fifteen participants to each disease group based on pragmatic qualitative approaches to theoretical data saturation (Guest et al., 2006, Suter, 2012), however once data collection had started it became apparent that much smaller numbers of participants, approximately eight, were needed to reach saturation in each disease group.

Participants were invited to participate by community pharmacists, general practitioners or a member of their care teams and handed a Participant Pack (see Appendix B). The Participant Pack contained a letter to the patient giving details of the study and inviting them to take part; a consent form for them to familiarise themselves with; a 'Registering an Interest Form' to complete and return to the research team if they want to take part; a stamped and addressed envelope; a 'Participant Information Sheet' containing more information about the investigation and contact details of the research team. Alternatively, general practitioners or pharmacists obtained the patient's consent to forward their contact details to the research team and the research team contacted the patient directly to discuss their involvement with the study. Once the research team received the participant's contact details (via post, telephone or email) they were contacted to arrange a suitable time and place for the interview. Participants were recruited for interviews until

data saturation had occurred in each disease area. Following analysis of the interview data, participants were recruited using the same technique to take part in focus groups however participants were also invited from local academic and professional networks.

Given the aim of the study was to explore patients' experiences of medicines adherence and the contention around measuring and defining adherence outlined in the earlier chapters, a decision was made not to define populations based on arbitrary definitions of adherence, such as adherent or non-adherent. As a consequence the sample had varying levels of adherence, from patients that had completely rejected pharmacotherapy, to patients who reported strict adherence practices. This was particularly useful during focus groups as differences between practices facilitated discussion.

An observation of recruiting through community pharmacy and general practice was that this population might still be described as 'adherent' as they were still engaged with healthcare such that they still visited their community pharmacist or general practitioner. Recruiting in this way then, does not include populations that are non-adherent to the extent that they do not visit their community pharmacist or general practitioner. The views of this population may provide further insight into adherence and empirical work should be pursued to explore this – as discussed in the final chapter.

***Inclusion and exclusion criteria***

Inclusion and exclusion criteria are outlined in the table below.

**Table 2. Inclusion and Exclusion Criteria**

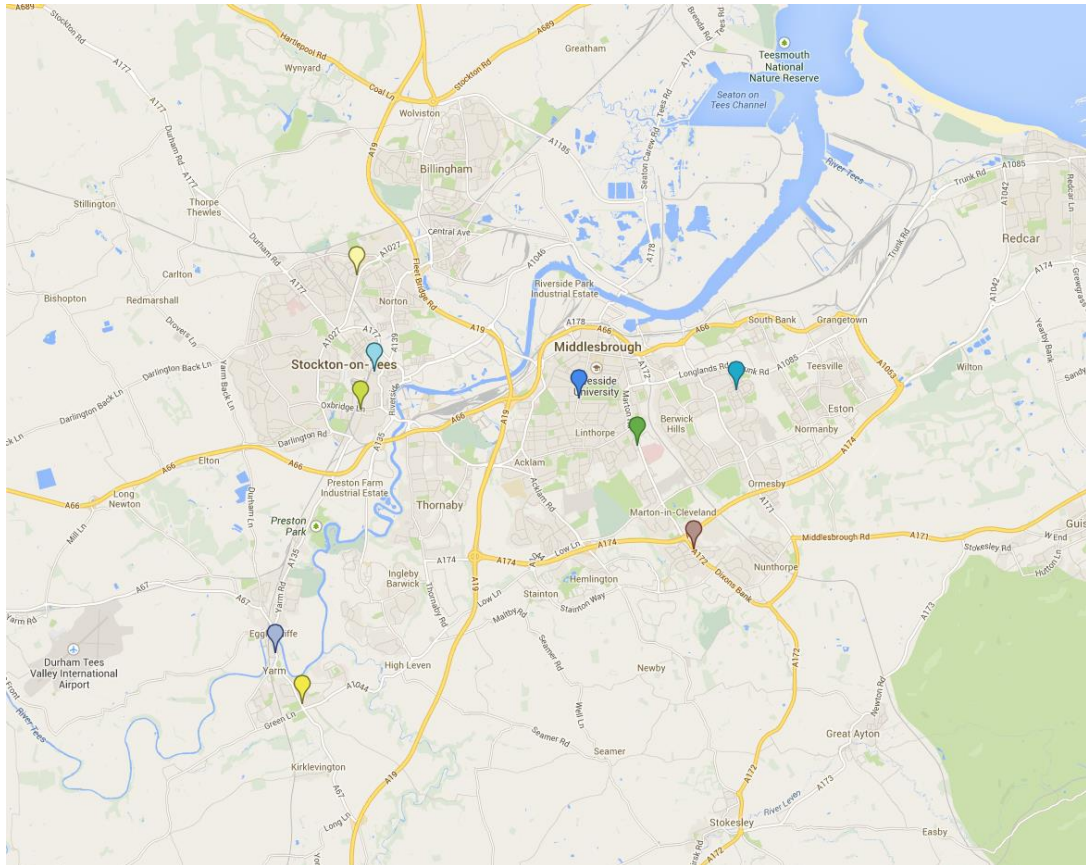
<b>Inclusion</b>	<b>Exclusion</b>
Adult (aged over 18 years old)	Does not meet the inclusion criteria
Willing to talk about experiences of medicines adherence	
English speaking	
Prescribed medication for cardiovascular disease, chronic obstructive pulmonary disease, gout, diabetes mellitus or cancer	
Has capacity to give consent	

***The pharmacies***

The study sample was recruited from community pharmacies across Teesside and screened against inclusion and exclusion criteria. In order to prevent coercion, colleagues in community pharmacies were briefed about approaching patients for inclusion in the study

and no financial incentives were offered either to patients to take part in the study or to community pharmacies to recruit patients. If the patient wanted to take part in the study they were given the means (a stamped addressed envelope) to contact the research team who would then be able to answer any questions the participant had or give them more information before arranging an interview with the participant. Participants were identified by community pharmacists and their teams when (including but not limited to) collecting a prescription, buying medicines, receiving a clinical service such as smoking cessation, medicines use reviews, new medicines services, minor ailment schemes or to obtain healthcare advice. The community pharmacy teams were not made aware of their patients' involvement in the study unless the patient told them themselves.

Pharmacies in Teesside were contacted to discuss their willingness to recruit participants to the study prior to recruitment beginning. Pharmacies were contacted through the professional pharmacy body (Royal Pharmaceutical Society), Local Professional Network and stakeholder events as well as existing academic networks. Geographically the pharmacies involved were from different areas of Teesside, including Yarm, Stockton and Middlesbrough. Pharmacies were selected to include a range of deprivation indices, including particularly deprived and particularly affluent areas, which, it was hoped, would result in a broad range of experiences of adherence.



**Figure 5. Community pharmacy participant identification centres**

Pharmacies were selected based on a sampling framework that ensured there was maximum participant variation in deprivation. This was done by mapping pharmacy postcodes to the Index of Multiple Deprivation (IMD) 2010 deprivation index (Department for Communities and Local Government, 2011) and selecting patient identification centres placed in the low, medium and high tertiles, although this did not guarantee that patients that use those pharmacies have similar deprivation levels. Pharmacies that agreed to take part were visited to discuss the study and the recruitment process and issue Participant Packs. The number of Participant Packs given to each pharmacy was discussed and agreed upon on an individual and continual basis to prevent pharmacies feeling pressured to issue the packs (i.e. one pharmacist was happy to receive 150 Participant Packs whilst another was only happy to receive 50). Seven-hundred-and-fifty Patient Packs were printed and issued across nine pharmacies for distribution to potential participants (based on a theoretical 7-10% response rate). The number of participants identified by pharmacists and given a pack was not recorded. The fate of prescription packs not given to patients was not recorded.

There was a perception from the School of Medicine, Pharmacy and Health Ethics Subcommittee that not all patients with cancer would receive medication from community pharmacy and that this may have presented difficulties in recruitment. Initially a view was taken that this was incorrect and that many patients with active disease or who are in remission will still take chronic medication that would be collected from community pharmacies. Additionally, patients with some cancers receive oral chemotherapy or adjuvant therapy such as tamoxifen, from community pharmacies. This view was generated from reflecting on personal clinical experiences of community pharmacy. However, during the study it became apparent that patients with cancer were not being recruited by community pharmacies. This issue was discussed with a selection of the community pharmacists that were identifying patients for the study, who explained that when they approached patients to be involved in the study, many patients felt that their involvement was not appropriate, as they no longer 'had cancer'. Whilst efforts were made to recruit through community pharmacy, ultimately patients with cancer had to be recruited through general practitioners.

### ***The general practices***

Four general practices from across Teesside were asked to identify participants for the study. General practice locations were complementary to the geographical locations of the community pharmacies and included additional areas from the surrounding Teesside area, such as Darlington. General practices were based in a range of deprivation areas (mapped to the IMD as for the pharmacies) however the majority of patients that were recruited through general practice were from areas of lower deprivation. General practitioners obtained patients' consent to forward their contact details to the research team, who then systematically contacted patients for involvement in the study. The number of participants invited to the study by general practitioners was not recorded. General practitioners were identified from professional and academic networks.

### **Data collection**

Demographic data was collected relating to participants' age, gender, postcode and consequently deprivation index, occupation, disease state and co-morbidity.

### ***Interviews***

Semi-structured in-depth interviews were used to elucidate the patients' lived experiences of medicines adherence to their prescribed medication, i.e. what they experience and how

they experience it. Each interview lasted between 60 to 90 minutes. After each interview, reflection with the senior research team discussed what went well, what could have gone better, and what would be done differently next time. The team debriefed either face-to-face or by email for the first 10-15 interviews and this practice was then reserved for interviews that had been particularly complex or difficult.

During semi-structured interviews participants are typically asked a number of open-ended questions, rather than closed questions, which enables them to describe experiences in their own words. Participants were invited to bring along their medication to be used as prompts throughout the interview or used their medicines as part of the interview in their home, this often involved retrieving medicines from cupboards in the kitchen or upstairs. Semi-structured interviews enable the focus of the interview to be shared between the researcher and the participant, unlike structured or unstructured interviews where the researcher or participant has complete control, respectively. This method therefore also enables the participant to share information they wished to disclose, as well as enabling them to hold back information they do not wish to share, which may be of a sensitive nature and is their prerogative. The disadvantage of using this method is that occasionally interviews can be challenging for both researchers and participants, particularly if the subject matter is sensitive or if the interview is lengthy (Crotty, 1998, Creswell, 2007).

Interviews were conducted actively, in so much that the researcher nodded, made noises of agreement and asked probing questions, rather than a passive interview whereby researchers say very little. Whilst active interview techniques potentiate the risk of bias, i.e. the researcher may give subtle indications as to what the participant should say, it enables the research encounter to reflect reality to an extent that participants share rich, detailed information as well as enabling the researcher to probe areas of interest or confusion (Holstein and Gubrium, 2004). In this study, conducting interviews in patients' homes enabled informal observations to be made in relation to medicines-taking paraphernalia, artefacts and products. During the interview participants shared and demonstrated their experiences of adherence, which were illustrated, annotated and enriched by being in the place where they most often experienced medicines use.

#### ***Location of the interviews***

Participants were always interviewed at a time and place convenient to them; this was most often their home however at the participants' requests, two interviews were conducted at the university, four in coffee shops and one was conducted in a local library.

Locations for interviews were conducive to obtaining data, i.e. not too noisy, in a safe environment where the participant and the researcher felt comfortable. All of the interviews were recorded using an audio-recorder and transcribed verbatim by the interviewer within a week of the interview.

### ***Interview schedule***

The interview covered participants' experiences throughout the duration of their treatment and participants were asked to describe if this has changed over the course of their treatment. Interviews used probing questions to explore patients' experiences of others in their experiences of taking medications; how involved they were with the decision to start and continue the medication or prescribing of the medicine; how they felt about the future in relation to taking medicines as they're prescribed; what their positive experiences of taking their medicines as prescribed were and what the negative experiences of taking medicines they had encountered; how they experienced taking and not taking medication as prescribed and how important they felt it was to take their medicines as prescribed. Participants were not asked to provide a full medical history or give detailed medical information other than to describe their experiences at the start of their treatment as part of their diagnosis.

The interview guide, shown in Appendix B, was explicitly vague to allow the interview to flow naturally and the essences of the patients' experience to be discovered - a more detailed interview guide would limit the flexibility and adaptability of the interview to the individual participant. This interview schedule also enabled participants to co-direct the interview, establishing a power balance between the interviewer and the interviewee. Where a participant had comorbid disease, questions were asked about the role comorbidities played on the experiences of medicines adherence.

In some interviews participants' spouses contributed to the research encounter. When participants' spouses contributed significantly to an interview and he or she met the inclusion criteria, he or she was consented and enrolled into the study as a participant (i.e. given an ID number). When participants' spouses only contributed sparingly or he or she did not meet the inclusion criteria, verbal consent was taken for their contribution to be included in the study findings (rather than being enrolled into the study).

### ***Focus groups***

Focus groups are an additional method used in this study. Focus groups provide valuable data collected in a group setting, enabling dynamic discourse between participants (Creswell, 2007, Crotty, 1998, Barbour, 2007). This method allows ideas to be formulated, discussed, and disputed by study participants and provided a method for collecting data relating to adherence interventions and to validate the interview findings (Bader et al., 2016). During the research encounter, observations can be made of how participants interact with each other and inferences made relating to the topic of discussion. For example, if a participant said something very quietly, whilst looking at the floor it infers something different to if a participant said something loudly whilst making eye contact with other members of the focus group. The downside of focus groups is that whilst a significant amount of data can be collected some data is arguably lost as it can be difficult for researchers to observe all of the interaction, or notice subtleties in larger groups. Additionally, transcribing the audio-recordings of focus groups can result in data being lost as participants speak over one another. Whilst researchers can attempt to limit this by establishing 'ground rules', one of the rich sources of data from focus groups is the spontaneous contribution of participants as they react to one another.

The use of the focus group method within phenomenological research requires critical reflection (Bradbury-Jones et al., 2009). As outlined above phenomenology is concerned with interpreting or describing experiences. Philosophically, as experience represents consciousness, phenomenological investigations have traditionally favoured research methods that elicit individual experiences. Some argue that focus groups contaminate individual experiences and are therefore incompatible with the theoretical foundations of the phenomenological approach (Bradbury-Jones et al., 2009). Despite this, some phenomenologists adopt the focus group method due to its suitability to answer the research question (Kooken et al., 2007a, Kooken et al., 2007b), to enable participants to expand on their experiences (Jasper, 1996) and to clarify, validate or triangulate findings (Côté-Arsenault and Morrison-Beedy, 2001, Spence, 2005, Carey, 1994). Indeed the focus group method has been argued to be congruent with descriptive phenomenological philosophy, in that the group environment facilitates the identification of individuals' assumptions, as individuals within the group challenge each other (Halling et al., 1994, Halling and Leifer, 1991, Spiegelberg, 1975).

Focus groups were convened after the interview data had been analysed to enable the findings from the interviews to be validated by participants (Bader et al., 2016, Côté-Arsenault and Morrison-Beedy, 2001) as well as to expand and explore additional aspects of the experience of medicines adherence (Jasper, 1996), particularly interventions used to improve medicines adherence. The data obtained related to views and opinions on the outcomes of the research; including the results of the thematic analysis and feedback from participants on potential solutions to improve adherence to medicines within the context of their disease state. Participants that had been interviewed were invited to attend a focus group however none were able to attend due to co-ordination difficulties, discussed below. As a result participants for the focus groups were recruited from community pharmacists, general practitioners as well as through local professional and academic networks. Three focus groups were conducted with a total of sixteen participants, seven in the first focus group, six in the second focus group and three in the third focus group, who had a range of diseases. Postgraduate research associates from the Wolfson Research Institute of Health and Wellbeing helped facilitate the focus groups. On balance the focus group method enabled rich data to be collected that in this study triangulated the findings, provided interesting findings of their own and also highlighted areas for further investigation.

#### ***Focus group schedule***

The focus group schedule can be found in Appendix B. The focus groups used a Powerpoint presentation to direct discussions – a copy of this can be seen in Appendix B. The proceedings were audio-recorded and additional, informal and unstructured, field notes of notable participant responses or behaviours were made. The focus groups lasted 60-90 minutes. Recordings were transcribed verbatim and circulated amongst the senior research team. Findings from the focus groups added context and validity to the interview findings as well as providing data of patients' views of interventions to improve adherence. Participants in the focus group were not made aware of who participated in interviews and were in control of what they disclosed, in terms of disease states and which medicines they take.

#### ***Location of the focus groups***

Focus groups were held at a time and place convenient to the participant, this was planned to be at the university or a public place local to the participants. The co-ordination of focus groups presented a difficulty in that finding suitable sites for focus groups to take place without financial implications and using sites that were accessible for participants was

challenging. Furthermore recruiting participants to be available at the same time and able to get to the same place also presented some challenges. After consultation with the participants focus groups were held at places most convenient to the majority of the group, this included two at the university and a community centre, for three consecutive weeks between October and November 2015.

### ***Other methods of qualitative research***

Other methods of qualitative data collection were considered but were not pursued as a method that was suitable as part of this inquiry. For example visual analysis and photography may have provided further insights. In this method participants are asked to take meaningful pictures of their experiences, which are then visually analysed to identify key parts of participants' experiences. This method was not chosen as it was expected that participants would take photographs of their medicines that might expose confidential information. Additional costs would also have been incurred, as cameras would need to be given to participants to enable parity of opportunity for those that did not have access to a camera.

Other methods include formal observations, where participants are covertly or overtly observed as they experience or go through a phenomenon. Researchers usually make detailed field notes that are analysed and can be synthesised with other forms of data. Formal observations were not used as this method was considered to be too intrusive to participants' and researchers lives, particularly as some participants might be taking medicines up to three or four times per day over a 12-hour period, requiring significant contact time between the participant and researcher.

The interview technique was also considered, as outlined above, active interviews were used rather than passive non-interruptive interviews. In this latter technique, the researcher usually asks one question and allows the participant to talk for as long as possible without interruption or engagement from the researcher (Health Experiences Research Group University of Oxford, 2015). Researchers must not nod or make sounds of agreement that might encourage the participant to speak about something in an attempt to allow the data collected to be determined entirely by the participant. This technique was not chosen, as passive interviews can be particularly difficult for novice researchers and can often make participants feel slightly uncomfortable if there is not an established relationship between the participant and the researcher. Despite acknowledging that these methods were not

appropriate for this study, adopting these methods to explore aspects of medication adherence may be appropriate in other projects.

### ***The participants***

Forty-one in-depth semi-structured interviews were conducted, the majority of which were conducted in patients' homes, at the University or in a public place. An additional sixteen participants were recruited to take part in three focus groups that were conducted at the university and at a local community centre to the majority of participants taking part in that focus group.

Key demographic details of participants are outlined in Table 4. The table below shows that the majority of participants in the study were retired (n=33) and male (n=34). Participants came from a range of deprivation indexes and were between the ages of 42 and 92 years old, with the median age of 69 years old. Over a third of the interview participants had co-morbid disease (n=32). Additionally, the third focus group included participants who were diagnosed with hypothyroidism and anxiety as well as one participant (P54) who did not wish to disclose her diagnosis. Whilst these three participants did not meet the inclusion criteria ('prescribed medication for cardiovascular disease, chronic obstructive pulmonary disease, gout, diabetes mellitus or cancer') and the study did not seek to recruit participants with these conditions, from an ethical perspective as the participants had attended the sessions after hearing about it from participants who were recruited via GPs or community pharmacists and wanted to take part, it was felt appropriate for them to be included, as these participants might provide alternative perspectives that would add depth to the study.

**Table 3. Participant Demographic Data**

Participant Number	Age	Gender	Level of Deprivation	Occupation	Disease Category	Comorbid	
1	01	83	Male	High	Retired	Gout	No
2	02	38	Male	High	Unemployed (ESA)	Diabetes	No
3	03	77	Male	Low	Retired	Diabetes	No
4	04	42	Male	Low	Police Officer	Diabetes	No
5	05	71	Male	Intermediate	Local Government	Gout	Yes
6	06	70	Male	Low	Retired	Diabetes	No
7	07	72	Female	Low	Retired	Cardiovascular Disease	No
8	08	92	Male	Intermediate	Retired	Cardiovascular Disease	Yes
9	09	71	Male	Low	Sales Exec (PT)	Cardiovascular Disease	Yes
10	10	77	Male	Intermediate	Retired	Diabetes	Yes
11	11	69	Female	Intermediate	Retired	Chronic Obstructive Pulmonary Disease	Yes
12	12	61	Male	High	Unemployed (DLA)	Cardiovascular Disease	Yes
13	13	52	Male	High	Unemployed (DLA)	Chronic Obstructive Pulmonary Disease	No
14	14	74	Male	High	Retired	Diabetes	Yes
15	15	67	Male	Intermediate	Retired	Diabetes	Yes
16	16	77	Male	Low	Retired	Cardiovascular Disease	Yes
17	17	80	Female	High	Retired	Cardiovascular Disease	Yes
18	18	80	Male	High	Retired	Chronic Obstructive Pulmonary Disease	Yes
19	19	63	Female	High	Retired	Chronic Obstructive Pulmonary Disease	Yes
20	20	73	Female	Low	Retired	Gout	Yes
21	21	81	Male	Low	Retired	Cardiovascular Disease	Yes
22	22	51	Female	Intermediate	Catering Assistant	Gout	Yes

23	23	60	Female	High	Unemployed (ESA)	Chronic Obstructive Pulmonary Disease	Yes
24	24	69	Female	High	Retired	Chronic Obstructive Pulmonary Disease	No
25	25	70	Female	High	Retired	Chronic Obstructive Pulmonary Disease	Yes
26	26	71	Male	Low	Business Owner	Diabetes	Yes
27	27	63	Male	Intermediate	Retired	Gout	Yes
28	28	70	Male	Low	Retired	Cardiovascular Disease	Yes
29	29	67	Male	Low	Retired	Diabetes	Yes
30	30	67	Male	Intermediate	Retired	Gout	Yes
31	31	76	Female	Low	Retired	Cardiovascular Disease	Yes
32	32	69	Male	Low	Retired	Chronic Obstructive Pulmonary Disease	Yes
33	33	52	Male	Low	Unemployed (DLA)	Chronic Obstructive Pulmonary Disease	Yes
34	34	55	Male	Low	Managerial	Cancer	No
35	35	75	Male	Low	Engineer	Cancer	Yes
36	36	65	Female	High	Retired	Cancer	No
37	37	61	Male	High	Retired	Cardiovascular Disease	Yes
38	38	67	Female	Low	Retired	Cancer	No
39	39	57	Female	Intermediate	Nursing Assistant	Cancer	No
40	40	70	Male	Low	Retired	Cancer	No
41	41	61	Female	Low	Retired	Cancer	No
42	FG1P1	56	Female	High	Housewife	Hypothyroidism	No
43	FG1P2	54	Female	High	Teaching Assistant	Chronic Obstructive Pulmonary Disease	Yes
44	FG1P3	88	Male	High	Retired	Cardiovascular Disease	No
45	FG1P4	61	Female	High	Cake Maker	Diabetes	Yes
46	FG1P5	56	Male	High	Construction Manager	Cardiovascular Disease	No
47	FG1P6	55	Female	High	Barmaid	Diabetes	Yes

48	FG1P7	78	Female	High	Retired	Cardiovascular Disease	No
49	FG2P1	69	Male	Low	Retired	Gout	Yes
50	FG2P2	79	Male	Intermediate	Retired	Cardiovascular Disease	No
51	FG2P3	78	Female	Intermediate	Retired	Cardiovascular Disease	No
52	FG2P4	53	Male	High	Employment Support Allowance	Cancer	Yes
53	FG2P5	76	Female	Low	Retired	Chronic Obstructive Pulmonary Disease	No
54	FG2P6	54	Female	High	Carer	No Diagnosis Recorded	NA
55	FG3P1	60	Male	Low	Local Government Officer	Gout	No
56	FG3P2	85	Male	Low	Retired	Anxiety	No
57	FG3P3	74	Female	Low	Retired	Cardiovascular Disease	No

A broad range of experiences were included in this study, adding depth to the data. What is noticeable for the age of participants is that the experiences of younger adults, aged less than 40 years old, may not be adequately represented within the study. Participants in this study were from white British backgrounds only. This was not intentional however does raise questions about the inclusion of black, Asian or minority ethnic (BAME) groups in research. Whilst a broad range of participants appeared to be included in the study, the experiences of younger adults and BAME participants may not be represented.

## Materials and equipment

Interviews and focus groups were audio-recorded using a Phillips three-microphone Voice Tracer. Recordings were stored on the device securely until audio files were transferred to a secure computer at the Wolfson Building (latterly the Holliday Building), Queen's Campus, Stockton-on-Tees, after which point they were deleted from the device – to minimise the risk of breaching confidentiality. Audio-recordings were transcribed verbatim in full, using a secure computer and anonymised using a standard anonymisation model - participant number, disease group, gender. Confidential material, including any paperwork that

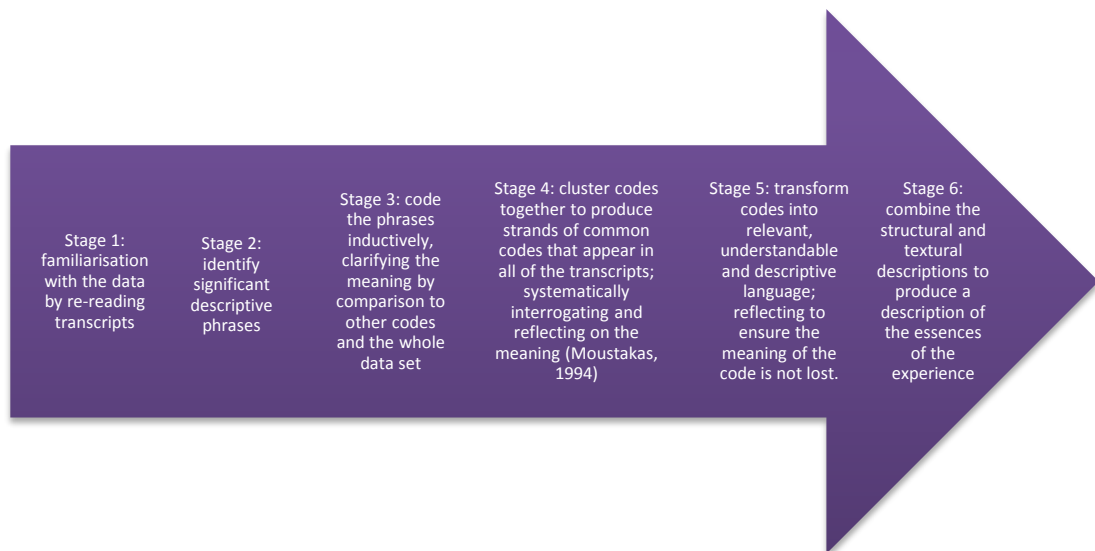
participants had submitted as part of their enrolment into the study was stored securely, in a locked filing cabinet, in a locked office, at Queen's Campus, Durham University.

## **Transcription**

Transcription occurred within a week of an interview or focus group, with salient field notes and observations added to the transcripts to add depth to the data. Transcripts were quality checked, which involved listening back to the recording of the interview whilst checking the transcript for errors or omissions. A standardised anonymisation process was used which assigned each participant with a unique combination of letters and numbers signifying their disease classification and gender as well as their participant number. Where patients discussed matters that might reveal their identity or the identity of the pharmacist or general practitioner who invited them to the project, alternative names were used to maintain confidentiality. Conducting the interviews and focus groups, transcribing and quality checking the transcripts provided preliminary familiarity with the data as well as developing a new set of transcribing skills.

## **Analysis**

The audio-recorded interviews and focus groups were transcribed verbatim. Thematic analysis explores the boundaries between opinions in the transcript to develop 'nodes' or 'codes'. Codes then form clusters of themes, which are synthesised to develop a structural and textural description of the phenomenon (Creswell, 2007). The stages of thematic analysis (Moustakas, 1994) that were used on the transcribed data are represented in the figure overleaf,



**Figure 6. Stages of analysis**

The stages outlined above not only describe conventional thematic analysis, but can also be mapped to transcendental phenomenological analysis. Analysis was conducted manually using paper and pen and also using NVivo10 [QSR, Melbourne], data management software. Thematic analysis was initially conducted after each interview had been transcribed, immediately prior to the following interview. This method of inductive analysis allowed nodes and codes to be assigned freely after each interview. Specific interviews that proved more difficult to analyse were given a greater time allowance for fuller and deeper analysis. Whilst the NVivo software enables the analysis to be presented in multiple ways, for example using tables or coding reports, a more dynamic reflection of the process can be seen in the manual coding and clustering as shown in Appendix A.

The analysis for this study reflects the methods described by Hibbert and colleagues (2002) '[we] used data from the focus groups and interviews to construct conceptual categories, which characterised major themes or issues. It was our intention that any generalised theoretical statements would be grounded in these thematic categories, which in turn were derived from the data. Although the analysis drew on the associated technique of constant comparison, a 'grounded theory' approach was not adopted' (Glaser B and Strauss AL, 1967). Codes were identified during an initial familiarisation with the data. These descriptive codes were used to identify what the participants discussed during the interview in very basic terms such as 'the doctor' or 'the drug'. Initial coding also included how the data related to phenomenon, i.e. positively or negatively. Associations were made between codes that were similar using the imaginative variation technique outlined by Keen (1975) that uses reflection to identify, scrutinise and corroborate links between codes

by examining the data. This developed the codes into thematic clusters such as 'survival' or 'necessity', which were then grouped together, using a One Sheet of Paper Method (Health Experiences Research Group University of Oxford, 2015). This was followed by the development of more refined, but more general strata, such as 'interaction' and 'identity'. Throughout the process was an awareness of many factors that may have influenced the analysis, such as the researchers' gender (male), age (mid-twenties), ethnicity (white, British) and social history (from working to middle class) as well as professional status as a pharmacist (Rathbone and Jamie, 2016). That given, the analysis can be described (as was done by Hibbert and colleagues (2002)) 'as a product of a process of construction between the respondents and the researchers, as not representing a single 'truth', but rather one possible story amongst many.' It is in this spirit that the analysis was carried out, informed by transcendental phenomenological theory and well-established qualitative methods.

## **Trustworthiness**

Trustworthiness in qualitative research can be argued to be made up of four principles; credibility, transferability, dependability and confirmability. These principles were embedded in the research methods and are outlined below.

### ***Credibility***

Credibility is concerned with assessing if the research actually explored what it set out to do. In qualitative research, methods that are well established such as what procedures and processes were followed during data collection and analysis, are considered to enhance the credibility of the findings (Shenton, 2004). Credibility was added to this study by following the analytical procedures of other studies, as referenced above, and generating questions to ask using approaches adopted from other phenomenological studies. Familiarity with participating organisations such as the community pharmacies and general practices was established through utilising the networks already well-known with the University as well as personal visits, telephone calls and email exchanges. However there was an awareness and prevention of over-familiarity with participating organisations that might have led to extraneous influences on sampling.

The study did not use a random sample, often regarded as being the gold standard for objective data collection in biomedical health research such as in a clinical trial, but rather a purposive convenience sample was used. This weakens the credibility of the findings as arguably participants could have been sampled due to unaccounted for influences from the

research team on general practices and community pharmacies. A random sampling technique may have avoided these influences however it may have also resulted in sampling participants who did not want to discuss their experiences of adherence and non-adherence, or identifying patients with such similar experiences that a breadth of experiences could not be collected. A purposive convenience sample allowed the research to proceed pragmatically. Multiple sites were used to identify patients, with sites based in differing deprivation index areas, to broaden the demographics of the sample – this adds to the credibility of the study as it enables a ‘more stable view of reality’ (Dervin, 1983) to be collected. Data was triangulated through multiple methods, of interview and focus groups (Bader et al., 2016). Finally, the credibility of the work is enhanced when it is compared to existing literature, as is done in Chapter 10.

### ***Transferability***

Transferability pertains to the generalizability of the findings to similar yet different settings and can be achieved through detailed reporting of the study site, setting, of the demographics of participants who took part, the number involved, data collection methods, the number and the time period over which the data was collected (Shenton, 2004). It is difficult to consider where the research may be transferred to and consequently reporting in as much detail as possible the contextual details of a study can enhance trustworthiness. The details of this study are documented throughout including details such as the location of community pharmacies and general practices used to identify potential participants, the location interviews and focus groups took place and the materials and equipment used. Reporting such detail enables the findings to sit contextually within the literature, rather than positioning the findings as ‘the true reality’, it allows the findings to be considered as a version of reality within the reported contextual limits. This enables a deep and rich understanding of a phenomenon to be achieved of which elements might be transferred to different groups.

### ***Dependability***

Dependability relates to how reliable the findings are – if another researcher conducted the same study, using the same procedural and organisational methods would a similar finding be uncovered? As noted by other qualitative researchers, this concept is difficult to address in sociological research (Shenton, 2004). Often research of this nature is highly contextualised and often theoretically framed to such an extent that findings are representations of a specific temporal and spatial reality that is dynamic and ever changing.

Often qualitative researchers, and particularly phenomenological researchers, are part of the research process. The researchers involvement in the interviews, focus groups and data analysis is accepted as inevitable as researchers form part of the constructed reality under investigation (Crotty, 1998, Creswell, 2007). It seems that the only way to infer dependability is to critically report the effectiveness of the methods of study, and the suitability of the methods to investigate the phenomenon under investigation (Shenton, 2004) as presented above.

### ***Confirmability***

Objectivity in social sciences is said to come from sharing research with other researchers (Banton, 2005) however it can be argued that confirmability of study findings can be inferred from transparent procedures in the form of an audit trail or from recognising predisposed beliefs through a reflective commentary (Shenton, 2004). In this study, confirmability can be identified and demonstrated in the epoché, whereby previously held knowledge and beliefs are considered prior to data collection and analysis which demonstrates the reflective nature of the study. Confirmability could also be considered to fit with how the findings can be confirmed readily by reality, although this can be challenged. In this sense, confirmability for this study could be inferred by the reader who might think 'is this experience reflective of my experience or the experience of someone I know?' Objectivity then is constructed from multiple different readers seeing something in the findings that they might confirm based on their experiences of reality. The findings of this study are confirmed by the comparison of data sets from interviews and focus groups (Bader et al., 2016), as well as other literature.

### **Summary**

This chapter has outlined that this study is underpinned by the conceptual framework of phenomenology, that a phenomenological methodology was the most suitably aligned with the research questions and described the materials and methods used. This chapter did not discuss the ethical considerations that were raised by the study, as these are covered in detail as an additional chapter in the Appendix C. The process of obtaining ethical approval for this study presented many challenges particularly in relation to the dual identity of being a pharmacist and being a researcher when investigating medicines use. Reflections of this process have since been published (Rathbone and Jamie, 2016), describing how pharmacists who adopt qualitative methods might straddle interdisciplinary boundaries through effective epistemological and methodological positioning. Whilst interdisciplinarity

has been achieved to combine social phenomenology with pharmacy in this study, further development of ethical frameworks might be explored to advance pharmacy education and research.



## **Chapter 4: Micro-social interaction**

This section describes the first theme that emerged during the analysis of the data. It is presented as sub-themes of personification, necessity, micro-social interaction and episodic short-term non-adherence. Micro-social interaction here refers to personal experiences between participants' identities and medicines' identities. Participants report the construction of medicines' identities, that is to say that medicines appeared to become social entities in participants' constructions of reality. Medicines were given identifiers that appeared to be not only based on the physical characteristics of the dosage form, but also on the subjective, felt and experienced, interaction with the medicine. Medicines were understood as being 'for' something, as 'doing things', having a constructed necessity, and this fed into the creation of medicines' identities, positing medicines as social actors, performing a role within a two-way micro-social interaction. Additionally patients described an understanding that within defined situations, medicines did not need to be taken. This chapter ends by discussing and interpreting the findings within the context of current psychology and social science theories, highlighting the novelty of the findings.

### **Personification**

Throughout the analysis of the interview data a strong emergent message described what happened when participants experienced adherence. They often described adherence to their medicines as an interaction with something, a relationship with an abstract being or entity; often speaking about that being or entity as if it were a person that was simultaneously embodied by physical medications but also an abstract identity. In the same way people are identifiable by how they look, where they can be found, what they are called and what they do or how they behave, a similar phenomenon was demonstrated when participants spoke about their medicines. It was clear in the interview data that these identities were not predetermined, or given, that is to say medicines did not inherently have known qualities, but rather knowledge about a medicine was constructed over time, as participants reported becoming more familiar with their medicine in a process similar to getting to know a person or people.

For clarity, this theme does not speak to the concept of personalisation, whereby medicines are used in such a way that reflects a specific relationship between a person and their medicine, though it does encompass this. Rather this theme speaks to the abstract attribution of qualities and characteristics to non-human objects, i.e. medicines, which then come to embody those qualities and concepts.

The data described a phenomenon where medicines were able to take on some person-like characteristics. These personified qualities of medicines, constructed the medicine as social actors within a patient-product relationship, is described below by Participant 4,

*“it’s a slower acting one, it’s just to, it’s just to, regulate your blood sugar through the night if you take a higher dosage but obviously the strength isn’t, the same the day-time. So on a night-time generally I take an injection of eighteen of whatever the measurement is but on a daytime I usually take up to about, with breakfast, maybe nine and that acts immediately you can feel it working straight away” P4, diabetes*

The personification of insulin is constructed around the patient’s understanding of what the medicine does, as he goes on to describe his insulin as ‘slower-acting’, that is the medicine is ‘acting’ in a particular way, ‘to regulate your blood sugar’. Insulin then becomes an abstract embodiment of regulation. The personification of insulin here identifies insulin as the regulator, performing an action and so being an actor. The focus on how medicines act, the function of a medicine was seen throughout the data, as shown below,

*“that’s either a sleeping tablet or a pain killer. I’ll go for pain killer. My doctor says I have a very jippy stomach and he can’t prescribe for me the tablets I should have, so instead of the one or two that would be better and have some reaction, they’re prescribed as a combination to try and fight the problem as it were. I mean I’ve been on them now for five, ten years in the main, but obviously not the ones to do with er...the...blood up and down and things like that” P10, diabetes*

This quote above describes the patient’s construction of ‘pseudo social norms’ around why medicines are used and the function of the medicine. In this quote, P10 describes his prescription being personalised to him due to his physical experiences of a ‘jippy stomach’. He identifies the medicines as either a sleeping tablet or a pain killer, suggesting that within the participants’ conceptualisation of medicines there are succinct categories. He goes on further to describe his medicines as ‘the blood up and down things’ and ‘to fight the problem’ – in all instances he describes his medicines as ‘doing things,’ as acting to ‘do’ something. He goes on to describe how he came to be taking that medicine, as a result of a ‘jippy’ stomach and how his prescription had been personalised due to the action and behaviour of the medicine, the interaction between his jippy stomach and the way the

medicine acted. Thus adherence is experienced as a phenomenon of personalisation and personification.

The construction of personified medicines' identities was also seen in other disease groups, such as in participants with COPD. Here too participants personified their medicines, describing and naming them as part of their role within the patient-product interaction. Just as a baker bakes or a builder builds, medicines were personified in that they took on these person-like qualities of defined characteristics; a sleeping tablet makes your sleep. Medicines were identified with names that were specific to each product. For example in the quotes below, the patient describes her prednisolone, a steroid used for the treatment of exacerbations of COPD, as 'prednisiline'. Another patient recalls one of their inhalers as the 'brown inhaler' but their other inhaler 'Ventolin'. This demonstrates a difference in the relationship between the patient and each of their medicines as unique social objects, rather than of interactions unique to the dosage form of the medicine. 'Ventolin' is a branded version of the drug salbutamol, which can be used to relieve breathlessness. It could be argued here then, that this participant's interaction with her Ventolin was more frequent, due to her experiences of chronic breathlessness and Ventolin's ability to relieve breathlessness. Consequently her familiarity with this medicine was greater, compared to her less frequent interaction with the 'brown inhaler' which the participant described acted as a preventer.

Medicines appeared to be given individual habitats or 'homes' and this was often related to how that medicine was taken and even where the medicine came from or was purchased. Medicines were also personified in that they were given occupations or jobs, that is to say specific responsibilities within participants' constructions of daily life. Participants grew to trust that medicines, as personified abstract identities rather than physical chemical objects, would 'act' in certain ways, to relieve symptoms, prevent symptom reoccurrence or maintain survival. Medicines were 'for breathless' or 'for phlegm' or 'for pain'. In this respect medicines came to have an identity, which participants came to know and trust over time through interaction. This is demonstrated in the quotes below.

*"well I get a chest infection and I know it's really tight and I'm really coughing and I'll be bringing phlegm up and then I'll go to the doctors and get either antibiotics or steroids..er prednisiline [sic]" P25, chronic obstructive pulmonary disease*

Here it is clear that each medicine appears to have its own identity. Within that identity was an understanding of what the medicine was called, where it should be kept and what the medicine did. In some instances participants reported an understanding that medicines were personified such that they could interact with each other, independent of the participant, that medicines could know one another,

*“It’s just me. I just hate taking loads of tablets. I just can’t see what one knows that the other ones doing when you’re pumping all these tablets down you.” P23, chronic obstructive pulmonary disease*

Judgements about the behaviour of medicines were made based on the physical appearances of the products, as in these quotes,

*“as soon as I went on the colchicine, they, they done the trick [...]...but looking at the size of them, they don’t look big enough to do anything... one of the doctors said they’re excellent...only little wee things... but he said they’re excellent but not very kind to your stomach” P1, gout*

Medicines were also remembered from how they acted, rather than specific names, as outlined by this patient,

*“my tablets on a daily basis but you had campaigns, ten days, because it knocks the stuffing out of you like, and at the end of it you’re weak...[do you remember what it was called]... [sigh] you know... some things you block out of your mind to be honest, and it wasn’t amoxicillin...[...]... amoxicillin that’s a penicillin, but I can’t remember the name. It was ‘the drug that was good for bowel cancer that is the best thing our NHS can prescribe’ so I just took a handful of that” P34, cancer*

In this respect, across disease states medicines’ identities appeared to be constructed as named personified actors; doers, knowers, blockers, stoppers, and openers. These abstract identities also included where products were located in space; by the bread bin, in the drawer, in the cupboard. Medicines were located in time; in the morning, in the evening, at 4pm, before the news, after my breakfast, as demonstrated in the quotes below,

*“I just take them first thing on the morning, go to, in the kitchen we have a cupboard and I would say people would call that the medicines cupboard, because it’s got my tablets in, in a box, just has, I don’t... I take the strip out and there are seven strips in that box, and I know I have to take them out and put them in the pot*

*beside me breakfast [sic] and I don't have to, I just automatically go to the cupboard" P17, cardiovascular disease*

*"I'm trying to think where it was you know... it wasn't Boots... erm, was it Sainsbury's I know I buy anti-inflammatories in Sainsbury's... I'm just trying to think what shop it was yeah, it was the pharmacy area, yeah it's the supermarket anyhow...[...]...I'm just trying to think where I was, I don't think I was out of town, but yeah, I thought, you know... yeah, but it's amazing that I don't think people realise they [emphasis added] can effect, especially when you're taking quite a few through the day" P11, chronic obstructive pulmonary disease*

*"they're in the kitchen by the bread bin,*

*[P18 wife] They're so he can see them when he's making his breakfast*

*They come in little boxes, and I've got them all in a plastic box, a morning box and a night... stay there and I'll show you" P18, chronic obstructive pulmonary disease*

In this sense, medicines became more than chemical compounds in dosage forms. Becoming the abstract embodiment of a constructed identity with the participant's perception of reality. One of the key components of medicines' personified identities was their capacity to improve, enable, and maintain survival. This focus positioned medicines, not only as independent, conceptual social actors within a patient-product relationship, but also within a broader pre-supposed social context, which is discussed in more detail in the section below.

## **Necessity**

Within this milieu of personification there was an underlying presupposition of the experience of adherence as a tool of survival or symptom management. At the heart of the experience was an over-whelming desire to live or continue to live as the participant had done, without the influence of disruptive symptoms on daily life. For patients in this study, many described feeling that they had no choice but to 'take medicines.' Medicines use was constructed as a way to survive across all disease states. Adherence as a tool of survival is seen in this quote, which is a long extract, from the interview with a participant with diabetes. Here the participant describes his 'personal' philosophy related to adherence directly linking taking medicines to survival and also highlighting that whilst adherence for survival is appropriate, this is dependent on one's social position – as someone with

dependants, a family, or children, and more general social norms concerning survival-seeking behaviours. P26 rationalises adherence as a choice between 'living a normal a life as possible' and 'wilting away', 'sitting down and waiting for their eyes to shut'. This locates 'survival' outside of the binary, life or death conceptualisation, but rather positions survival within the sphere of adherence as the survival of the patient's everyday life. This desire to survive then, describes the experience of medicines use as a social phenomenon of survival,

*"My own philosophy is we're only here once yeah, I don't want to live forever, I'm not one of these people who will just keep taking tablets and taking tablets whenever for whatever and live until 155, I think when my day of not being useful or not enjoying life come then that's your term you know, so... I don't know how you could encourage somebody, that has... whatever philosophy about not taking tablets...you have to get them with some type of message across to them to say, you have to do something for yourself, if you want to first of all have a healthier life, sometimes if you stop taking tablets and you're out of breath and you're not very active, obviously once you get to that stage, it breeds more inactivity, less this, less that, less the other and you just end up wilting away, and some people are happy to die like that, they just sit down and wait for their eyes to shut... for somebody that is of a reasonable age who doesn't want to take tablets to help them have a normal a life as possible with the aid of tablet, I just don't see any reason why they're just not going to do it. They can't like their-self... and they're only thinking of themselves if they do do that especially if they're of an age where people are dependent on you, like if you're the husband and you're married with a wife and kids and what have you, these people don't deserve to be left on their own with me being selfish, which they are really" P26, diabetes*

Here adherence is described as an experience of heart and mind, a personal belief system or approach to life and medicines taking. Participants in other disease groups also appeared to identify adherence, and 'medicines taking' as a necessity for continued survival, demonstrating that despite disease group participants' experience of adherence to medicines had some transcendental qualities,

*"no, no, it's not a matter of getting fed up of them, it's that if you want to live, you've got to take them...[...]the box is there, I know it's there and I know I have to*

*take them, it's either take them or die, simple as that isn't it?!" P18, chronic obstructive pulmonary disease*

*"if it wasn't for that [medicines] I don't think I would be here today, taking those," P19, chronic obstructive pulmonary disease*

*"I don't think they give you these tablets unless you need them... and if you stop taking them then you're putting your life back at risk, therefore if anything happens then you're putting your life back in risk, it's the individual person... it's up to them, you can't twist their arms and put it down their throats, I don't think they would give you them if you didn't need them" P7, cardiovascular disease*

In participants with gout, survival was not directly linked to adherence, however medicines taking for other conditions, was linked to survival and so medicines taking overall was considered a necessity,

*"Well it's life or death isn't it with me heart but you never hear of anybody dying of gout?" P30, gout*

Despite a poor association of gout medicines with survival, P22 felt that even though she did not want to take medicines, due to her gout symptoms, she felt she had no choice,

*"I personally think it must be a positive thing because...you must need them... to have to take them, erm, and they're helping you aren't they, I feel, erm... would I prefer not having to take them... yes course I would but, you know.... [why would you prefer not to take them?] ... because I'd rather not have to take medication if I didn't have to, because who knows really what it's doing, mmm? Yeah, who really knows what it's doing, what's it's really doing, what it's kicking off or whatever. You don't know do you? Because everybody is different, so... if I had the choice, I would prefer not to have to take them but right now I don't have that choice" P22, gout*

The necessity of adherence here then, rather than being intrinsically linked to survival, was more strongly linked to the relief of symptoms, and the 'survival' of the participant's everyday life, embodying participants' experiences of adherence as one of necessity. The necessity of adherence was internally negotiated as the patients' desire to survive and maintain everyday life; how the product acted physically, to cause side effects or relieve symptoms; and how society (embodied as healthcare professionals, friends and family, the

media) acted in response to patients' experiences of medicines use. This can be demonstrated below,

*"no matter how much they tell you what is going on no-one can tell you what chemotherapy is like til you've had it, and it absolutely wiped me out. I couldn't, I couldn't believe that you could feel that dead, and just on a drug, it was an extraordinary feeling, it was, about six days after I'd started I was just lying on my bed... I didn't care about anything, death would have been a perfectly reasonable option, I didn't feel ill, urm, I just felt so weakened, so didn't care, completely out of it, and I rang up, I've always had people I can ring up and I rang up this nurse and she had a word with the consultant and they said just stop taking the tablets and I did and within a few days I felt more like myself but of course the tablets were working with the infusion and erm, so I became aware after a little while I'd really done myself no favours at all as far as the cancer was concerned but I really did feel so awful at the time I couldn't contemplate going on because you really have no idea how terrible you're going to feel. I mean friends that have been there since I've tried to tell them this so that they're more aware of it, and I did get a marginal reduction in the capecitabine for the rest of the, the other sessions and erm, I'm frankly not sure that helped at all but by then I knew what I was going to feel like so I was able to endure it better." P41, cancer*

In this quote it is possible to delineate the participant's negotiation between necessity of chemotherapy to treat cancer and potentially live longer; her experience of a negative relationship with her chemotherapeutic agent; and her experience of how society responded to her medicines use. Here her experience of side effects within a patient-product relationship sits within a wider interaction with the rest of society, initially enacted through her friends, that constructed chemotherapy as a 'side effect producing agent' and, latterly enacted through healthcare professionals, that constructed chemotherapy as an agent whose actions could be limited by reducing the prescription. This episode of non-adherence, is essential to her experience of adherence, when she re-identifies the chemotherapy, not just as something that makes her feel 'dead', but as an agent of survival, she says 'I'd really done myself no favours' and goes on to say that on her adherence to her next cycle, 'by then I knew what I was going to feel like so I was able to endure it better,' here the participant appears to be describing an experience of adherence

that is underpinned by a desire to survive, despite the experience of significant side effects, when the medicine has been identified as a necessity.

The experience of 'getting to know a medicine', constructed a personified identity incorporating the products necessity into how it should be used, were described as being constructed through continued interaction with the product on very personal level. This is described in the next theme, as micro-social interaction.

### **Micro-social interactions with the medicine**

This theme can best be demonstrated with patients' description of their use of co-codamol. For this participant co-codamol was prescribed for pain, this is prescribed 'two tablets four times a day', however that the medicine was prescribed for pain, and through exposure to the medicine meant that this participant identified the medicine as for sleeping or relaxing, meaning that the participant used the medicine as a hypnotic each night, rather than as an analgesic when required. The indication of co-codamol for pain is knowledge that is generated socially, from socialisation with prescribers, healthcare professionals, the media and, importantly, exposure to the product and experiences of the product relieving pain. However here the participant's interaction with co-codamol, how it acted and made her feel, was internalised and constructed a belief that co-codamol was a hypnotic. As patients construct an understanding of what medicines are for and how the medicines do what they do, the medicine becomes a social entity that is interacted with. Adherence to the medicine is the manifestation of this social interaction between the patient doing something and the medicine doing something.

*"No I haven't been on tablets, all I take is three inhalers and two co-codamol isn't there? I take them because... on a night it relaxes me," P24, chronic obstructive pulmonary disease*

How products acted micro-socially to make patients feel in relation to their symptom control, immediately and over time, fed into the identity of the medicine,

*"Yeah I think it was pain killers, I was probably started on hydrocodeine and I've been on them ever since, and I know if I don't take them I feel pain in the side of me face, back of me neck, not on the same day, the following day" P10, diabetes*

with the experience of medicines use feeding into patients' feelings towards specific products,

*“when I first went on them I didn’t always do it, I would admit , erm... maybe if I just felt me chest a bit tight then yeah, ‘oh I haven’t used me sprays’ you know... erm, but as time... over the last couple of years, erm, then yes, I’ve appreciated them much more than maybe I did at the beginning, you know, I do believe they help,” P25, chronic obstructive pulmonary disease*

Personified medicines’ identities then interacted with participants over time, enabling further more detailed contextual knowledge to be constructed relating to the medicine’s identity. Interactions with medicines over time appeared to generate feelings of familiarity, habit and ease, despite previously held beliefs about medicines. These interactions then, whilst still informing, constructing and reinforcing beliefs and knowledge about medicines’ identities and adherence as a mechanism of survival, were experienced as routine. These interactions are described as such in the quotes below,

*“ I don’t see it as a problem, I mean lots of people like routine anyway don’t they? If they get into it then you just do it” P5, gout*

Despite being socially-informed as in the quote above, participants were able to deviate, and create their own personal interaction with the medicine by repackaging it,

*“with reluctance it’s just habit forming. And er, what I do, I am a naughty boy, I know it’s a naughty boy, I have these trays and I have these trays and I put all the medication out for the week” P3, diabetes*

Experience of these micro-social interactions with the medicine helped patients construct ways of dealing with problems associated with medicines taking,

*“I’m fine now because I’ve been diabetic so long I don’t really come across those problems like that so much,” P4, diabetes*

Routine interactions were also informed by patients’ experiences outside of the sphere of medicines use, informed by interactions with family as in the quote below,

*“Well I think like anything, me being an engineer I was used to having procedures, you know, processes erm, now, when I first went onto them tablets, my wife, bless her, she carried me all me life, but she would sort of organise them and that and then, she wouldn’t actually organise them, she would just say have you had your tablet and I would say oh alright, I’ll have me tablet but no, I think you just get into the routine and then it become second nature to you to be truthful” P40, cancer*

Micro-social habits between the patient and product were able to withstand the influence of constructed knowledge from outside the patient-product relationship, as demonstrated in the quote below,

*“well I take them at night because when I first got them it said take them at night, but then when I spoke to the pharmacist I said do I have to take them at night or can I take them all at the same time and he said yes you can if you want we just did that till you got used to taking them, but as I’d always taken them at that time of night I just carried on” P7, cardiovascular disease*

The habitual, routine nature to these interactions appeared to construct adherence as a ‘given’ phenomenon, something that was ‘just done’,

*“I wouldn’t say you come resigned [sic] but you just come to taking the tablet.” P26, diabetes*

Over time, micro-social interactions between the patient and product were able to embed medicines taking as routine, despite dislike of medicines,

*“It doesn’t really bother me, I just take them you know, a habit, put it that way, a habit you just automatically take them and hope that they’re going to do their work, I can’t say that I’m that keen on taking them but you do” P20, gout*

Micro-social interactions also appeared to be focused around other aspects of everyday life, including getting up in the morning, preparing for sleep and eating,

*“now it’s just a part a routine thing now, erm, and in the morning and in the evening, before the evening meal I give myself a jab” P6, diabetes*

The interaction between social entities (the patient and the product) represents a pseudo-socialisation, a micro-social interaction, where patients normalise and habituate adherence to their medicines so that their medicine fulfils its perceived necessity within the patient-product relationship. Socialisation here then, reflects the interactions between the patient and the product, generating participants’ understanding that the medicine can be taken habitually, automatically and in a ‘given’ way to achieve an outcome and fulfil necessity. This is further demonstrated by P13, in his experience of adherence that socialised him into using the medicine in multiple ways for multiple purposes, demonstrated here in relation to his experience of adherence to amitriptyline,

*“Now amitriptyline is not only for, it’s for mental illness, it’s a drug to stop panic attacks but they’ve found it can also be used to boost pain killer response, because I can’t have an aspirin-based tablet because, it suppresses your breathing, which isn’t good, to when my breathing is suppressed I get lung infections but it also can calm you down, because obviously [I’ve] been ill for fifty two years it can, I have days where I just can’t cope... yes, I mean it depends on the pain, if I’m having a good day I only take one, and the sometimes me arm, I’m in horrendous pain, then it’s two, because it also helps with the pain in my leg which I get now,*

*[Do you have to tell them-]*

*No, no, me GP knows me well enough that I can more or less self-manage, I’ve been taking tablets since I was four or five, as long as I’ve been old enough to swallow a tablet I’ve been taking tablets’*

*[do you ever stop taking the medicines on those days]*

*Fortunately no, because I know it’s be worse for Jo [pseudonym of carer and wife], if I go into crisis, it’s bloody awful, it means paramedics, it means a trip to the hospital,” P13, chronic obstructive pulmonary disease*

This participant had had life-long respiratory disease including multiple diagnoses and consequently had experienced significant social interactions with healthcare professionals and medicinal products. In his quote above, he describes the multiple necessities of amitriptyline. P13 goes on to describe that his micro-social interaction with the product is informed by macro-social interaction, as the social outcome of non-adherence would have negative ramifications for him and his wife and carer, Jo’s, lives more broadly. It appears here then, that interactions between the patient and product, on a micro-social level, sit within broader macro-social interactions with wider society (this is discussed further in the next chapter).

The quote also demonstrates the participant’s confidence to use the medicine based on the behaviour of the medicine itself in relation to managing his symptoms and ‘working’. The participant has ‘got to know’ that his interaction with amitriptyline can vary, the identity of the product includes that it continues to act in the same way, despite not being interacted with in the same way, i.e. the medication continues to work despite being taken. This phenomenon was seen in multiple patients and is described in detail below.

### **Knowing it's okay to be non-adherent: episodic short-term non-adherence**

Participants described this phenomenon of short-term non-adherence with some of their medicines, where they might miss one or two doses or 'a few days' worth of medication and that 'everything worked out okay'. Participants reported a set of their own principles or routinized non-adherence practices, relating to pre-determined plans of 'what to do' if a medicine was missed by a short time (for example an hour or so) compared with a longer time (half a day to a day). Participants also described not being able to go longer than a few days without their medicines. This seemed to be as a result of established beliefs of the necessity of adherence, in relation to survival, as outlined in the quote below,

*"oh yeah, but what I don't do, I won't take them if I'm missed them in the morning I won't take them late on of an evening if I'm going to have to take them of a night-time, because that, in effect, on some of them is doubling them up – if I've survived that long, I'll survive another couple of hours [laughing]" P3, diabetes*

Reminder devices were not described as preventing missed doses in relation to the timing of doses,

*"I've got somebody round and we're talking, the phone goes off and I think 'oh tablets' I'll remember that but of course they're there for another hour maybe, I'm still talking, and when they go I haven't thought anymore about the tablets so the alarm is pointless [laughing] yeah, I do [not take them], I wouldn't say I do it often, but I've certainly done it several times" P9, male, cardiovascular disease*

However patients described that beyond a few hours or a few days, non-adherence may become problematic,

*"[How would you feel if you'd ran out of tablets and you couldn't borrow any, how would you feel?]*

*If it was just for a day, I'd be all right, but if it is more than that, I think it would start to have an effect on me" P18, chronic obstructive pulmonary disease*

*"when I forgot to take it I thought 'oh my God, I've forgotten to take me tablet, I'm going to get another lump, what's it going to do' [high pitched voice] yeah, all in the same day, I think it was, I'd realised in the afternoon that I hadn't taken it, oh it wasn't like it was a full day I don't think. But yeah, I did panic a little bit and I don't know why I should, but you know you think, is it going to make any difference if I*

*miss one? Well you know it's not really, this was at the beginning, I think this was in probably the first year, I mean, and you do think every time you get a new symptom, or you find something that's....wrong, that shouldn't be there, you think 'oh my god, has it come back again' but as time passes, you get to be a little bit more, 'calm yourself down a little bit, missing one tablet isn't going to make any difference' [angry voice] [laughing] I did worry at the beginning you know, if it would have any effect on me if I did forget but I'd only forgotten for about six hours so really, you know, it's a bit silly you know, looking back on it now you know, 'get a grip' [laughing]" P36, cancer*

Micro-social interaction then seemed to be constructed by the participant's own understanding of how the medicine 'worked' and acted as part of the products perceived necessity. Participants behaved as the medicines they were taking needed them to behave, to fulfil a medicine's perceived necessity. As participants personified their medicines they appeared to construct lay pharmacology, suggesting that medicines are able to interact with each other as well as the patient, which fed into an understanding of the 'role' of the medicine. This was built on knowledge generated from exposure to healthcare professionals and peer-patients; by family and friends; and from sources of information on the internet, television, printed press, and radio, whereby participants appeared to be socialised into adherence and construct an understanding of how the medicine worked and what the medicine was for, based on socialised knowledge generated over time,

*"once you're on them, then that's it... oh yeah well especially with the allopurinol, he said once you go on the medication, he said you need to take it all the time you can't just switch and stop you'll have to take it, I presume because that's making you body work in a certain way, and that reduces the, this acid" P5, gout*

This knowledge of how medicines worked, and notions of the body as 'a system', appeared to be generated from interactions with healthcare professionals. Where dissonance or disagreement occurred between knowledge from micro-social and macro-social interaction, non-adherence could occur. This was particularly apparent in P2, who was experiencing an episode of non-adherence during the interview. He had had an altercation with his specialist diabetes nurse who had 'called him morbidly obese' and discontinued a prescription of liraglutide and restarted a prescription of metformin. P2 had a history with metformin and suffered side effects without really perceiving any benefit from the treatment. When the specialist nurse prescribed this new regimen, P2 crumpled up the

prescription and threw it at the pharmacist. He explained during the interview that he had gone almost a week without using any of his medicines, including his anti-hypertensive and aspirin.

*“because I was told I had to take it... I was told that this was the medication that you need to take... so I thought well, because obviously I’ve never been on it before... obviously, my body is.... Getting used to it... or however it does... when you start taking medication I think... I’ve been told your body takes a while for it to get into your system... and start doing the job that it’s meant to actually do....[but then the Specialist Nurse said] Injections have stopped as of now. You no longer use them. It’s wasting everyone’s time. It’s not doing you any good. Stop them. I’m going to put you back on metformin ... [so]...I’ve decided that my medication is stopped until [the GP] sorts it all out. I’m not taking any more basically. I’ve had enough. Every doctor.... Like... other doctors that I’ve spoken to, other professionals that I’ve spoken to... are all telling me that I should be on insulin*

***and what do you know about insulin?***

*I don’t... I don’t know nothing. They just say because of your levels and the way you are you need to be on insulin to help control it*

***and this woman,***

*was just like no, not at all and it’s because you’re morbidly obese, and that is why”*

*P2*

Although P2 is describing non-adherence, this had thus far only lasted less than a week and was within a context that he had been told, ‘by other doctors and professionals’ that he should be on insulin rather than his current regimen of liraglutide. Prior to this the participant reported being adherent to his liraglutide, getting on with it ‘really well’ and ‘just taking it’. The participant’s reaction then, and experience of non-adherence to liraglutide and other medicines, could be argued to be socialised, in that his behaviour is the result of interactions between different social actors – the specialist nurse, his GP, ‘other professionals’ as well as micro-social interactions with the product, metformin and insulin (as a personified social entities). The specialist nurse appears to be acting out-of-sync with other actors the participant is exposed to and interacts with, who say that he *should* be on insulin. The internalisation of this belief, his experiences of using medicines previously and his continued survival, his short-term non-adherence is normalised to an

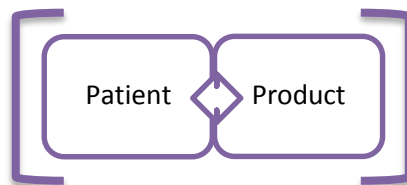
extent. Unfortunately it was not possible to follow P2 up to explore his experiences of non-adherence further however the normalisation of short-term non-adherence may be an area for future work.

Episodic short-term non-adherence represents a negotiation between the constructed identity of a medicine including its pharmacology, its necessity and its action within a routinized, micro-social patient-product interaction

### **Interpretation and discussion**

These findings describe patients' experience of adherence as a phenomenon that is underpinned by the construction of medicines as social actors, based on their ability to improve physical symptoms, extend binary survival and maintain patients' everyday life.

These findings provide support to arguments that position adherence as a phenomenon of necessity (Horne and Weinman, 1999, Horne et al., 2013, Horne R et al., 2006 ). Presenting the construction of beliefs about medicines and necessity of adherence as an integral part of the experience of adherence across disease groups. This work offers a description of adherence as composite of a micro-social interaction, between the product and personified product identity. This is represented in the figure below.



**Figure 7. Patient identity and product identity**

This perspective identifies that adherence represents a micro-social relationship and presents pharmaceutical products as more than their objective chemical properties. This work acknowledges the social nature of pharmaceutical products; describing patients' lived experience of adherence, as a two-way relationship between social entities. The personified pharmaceutical product is able, in the patient's mind, to influence and change the behaviour of the patient by relieving symptoms, causing side effects and maintaining survival, and equally in the patient's mind, the patient is able to influence and change the behaviour of the personified product, through adherence and non-adherence. Patients' lived experience of adherence then can be described as a form of socialisation, where one actor can influence and change the behaviour of another (Thomas and Evanston, 1967).

Adherence posited as the performance of behaviour in a two-way relationship, presents a perspective of the phenomenon typified by medical sciences. That medicines act within medical sciences refers to pharmacological or physiological action, for example, 'a beta-agonist acts on beta-receptors'. This pharmacological knowledge, that within medical sciences is very specific to particular drugs and physiological functions, appears to be transposed into a representation of a social interaction within a patient-product relationship. It is possible to imagine how expert scientific beliefs concerning the pharmacological action of a drug might be transformed into lay representations, for example as expertise moves from the laboratory bench 'a beta-agonist acts on beta-receptors', reaches the clinic as 'a beta-blocker that acts on the heart', is experienced in society as 'the blue one that acts on my heart.' As the product, and knowledge associated with product, moves into the pharmacological sphere and into patients' homes and life-worlds, it is transformed from an entity of pharmacological action to social action.

That products obtain social identities echoes findings by Whyte et al. (2002), however the synthesis of this perspective with patients' experiences of short-term non-adherence and how this goes towards the construction of the product's social identity is a novel insight. This finding argues that episodes of short-term non-adherence mean that some products become 'miss-able,' that they are able to be missed, and that this becomes part of that product's social identity. This represents the product behaving in response to the patient's behaviour. When patients' behaviour changes in the short-term, some products continue to behave normally, preventing symptoms and maintaining survival. This feeds into beliefs about the necessity of the product in that whilst adherence may be a necessity in the long-term, short-term episodes of non-adherence can be negotiated within the patient-product relationship.

## **Conclusion**

This chapter has argued that patients' lived experiences of adherence are underpinned by the construction of medicines' identities. Getting to know medicines through personification and assignation of personal characteristics to pharmaceutical agents constructs these products as social actors. Medicines enact behaviours that, through micro-social interaction with the patient, construct the patient's perceptions of necessity of adherence, as well as constructing beliefs and habitual medicines taking practices that includes episodes of short-term non-adherence.

That medicines use can be interpreted and described as a social interaction highlights the importance of understanding the adherence phenomenon from alternative perspectives, that might challenge normative theories of adherence that locate adherence as the outcome of modifiable and non-modifiable facilitators and barriers, to medicines use. Within this study, rather than adherence being conceptualised as a calculable, objective enactment of a patient behaviour, adherence can be conceptualised as a two-way experience, both constructed by and constructing patients' perceptions of product identity, necessity and medicines taking practices. This alternative perspective provides a new lens to consider the adherence phenomenon.

Presenting adherence as an experience of social interaction between the patient and the product provides opportunities for further analysis to elicit how patients experience this phenomenon. This chapter has argued that participants' construction of personified product identities (including perceptions of necessity and when medicines can be missed) occurs through micro-social interaction. The next chapter argues that this micro-social interaction between product and patient takes place within a broader, macro-social interaction with wider society that feeds into the construction of both the product's identity and the patient's identity.

## Chapter 5: Macro-social interaction

This section describes how interaction with wider society constructed medicines taking practices across disease states. 'Wider society' here refers to normalised social beliefs, social norms and practices that are internalised and inform individual practices. These individual practices, in turn, inform social norms, reinforcing individual behaviours and societal beliefs. Analysis of data suggested that medicines taking practices, including adherence, non-adherence and the use of interventions, were informed by macro-social interactions, stratified here as interactions with lay beliefs and practices, including those of friends, family and peers; with expert opinion, including healthcare professionals and evidence-based medicine beliefs; and with the mass media, including newspapers, the television and the internet. Knowledge and opinions from each of these domains was described as informing patients' medicines taking practices, within the context of patients' experiences of micro-social interaction with the product.

An important element of macro-social interaction was how this interaction constructed participants' beliefs about medicines, particularly the necessity of medicines, and informed medicines taking practices as part of the patient's identity.

### Interactions with friends, relatives and the media

Knowledge about medicines' identities and how medicines should be taken, stored, and interacted with were constructed through interaction with non-professionals and lay knowledge. Adherence as a socially normalised phenomenon appeared to be reinforced by social relationships.

*"I do it for my own good, but it's not only, I don't think it's only for your own good, you want to live as long as you can, you want to see your kids and your grandkids grow up and that's what my aim is, it's to see my grandkids grow up" P19, chronic obstructive pulmonary disease*

*"I think if I didn't have the boys maybe I would have given in and thought bugger this but because I've got so much, it's worth taking the tablets and fighting for it" P23, chronic obstructive pulmonary disease*

Interactions with lay practices were also reported, as below. This participant describes how his mother-in-law used medicines,

*“my mother-in-law she had to take pills every day and she had dementia, and when she realised, she must have realised, I mean she really was away with the fairies, when she realised, deep down, that she’d had enough, she was in a care home and her hand had seized up, she couldn’t straight it up, and when the carers weren’t watching she was spitting her drugs out and shoving them in her hand, and eventually, there were so many, they were popping out the other side and falling out you know! And erm, she’d basically had enough, she stopped eating, she stopped drinking and she basically said to my wife, she said ‘I’ve had enough, I’m fed up’ and she just, went.” P32, chronic obstructive pulmonary disease*

In this retelling, medicines non-adherence represents a loss of the will to survive in severe illness. Constructing adherence as practice of survival, here medicines taking practices were passed from mother-in-law to son-in-law. In this sense, knowledge about medicines was generated socially without effort, with knowledge constructed according to defined situations. Participants reporting adherence behaviours and practices based on the experiences of interactions with, and lay knowledge obtained from, others,

*“it’s just some ginger I’ve had, my daughter must have been reading, and it’s apparently, the ginger, it’s good for anyone with COPD and the cough, and I’ve been having it, just drinking, and honestly it does, yeah.” P11, chronic obstructive pulmonary disease*

Medicines taking practices were described as a learned behaviour, ‘inherited’ from parents, particularly in relation to the dislike of medicines taking,

*“I mean my mother doesn’t, she doesn’t take stuff unless she has to either, mmm, even me father he never took anything, you even had to force him to take his blood pressure medication I think, mm,” P19, chronic obstructive pulmonary disease*

Constructing knowledge and medicines taking practices from lay sources, such as the media and family and friends, was also apparent where medicines were not necessarily pharmaceutical in nature, but could be described as nutraceuticals,

*“my mam was reading the paper and there was this local chap, who had had bowel cancer who was terminal, now I don’t believe whether he is still alive, I don’t know, but he’s taking this concoction of stuff and I looked into it, and I thought bollocks, I’m going to buy that. And again, I take this set of tablets, most days, when I*

*remember, when I can put them in my tablet dispenser, I'll bring them down. [...] So that's my little anti-cancer." P34, cancer*

In P34's case, his understanding of what his medicines were for appeared constructed from social interaction with his mother and the media. In this sense, the knowledge generated from these wider societal interactions and the interactions themselves appeared 'given', predicative, 'just known meaning that adherence was 'just done', as shown below, first in relation to the spatial elements of adherence (i.e. where medication is taken) and then secondly in relation to learning about medicines,

*"No, I've always taken it upstairs, I think yeah, I did it the same when I was taking the HRT, I did that at the same time everyday as well, you know...I've never thought of [why], it's just something, it just feels right, do you understand? it's just, maybes, where we keep.....mind you I do know yes, my mum and dad used to keep theirs upstairs, maybe inherited, maybe, because me dad was on medication because he had chronic obstructive airways disease, and the only thing he kept downstairs was his inhaler, everything else was upstairs. Yeah. I'd never thought of that. Yeah. ... my mother kept hers in her knickers-drawer [laughing]" P36, cancer*

*"I don't read the buff, but my son-in-law says 'if you get some different symptoms it might be one of those,' and I said 'well I don't want to know what the symptoms are,' he said 'yes but you should read the symptoms'" P17, cardiovascular*

Interaction with the media also led to personification of medicines, as well as generating ideas about how medicines should be taken and what should be done as part of medicines taking practices, as below,

*"I would probably read more on the Internet to try and find out more. It's like when you get a new pet you want to know what's best for them and what you should be doing, gathering information" P4, diabetes*

Interaction between the media and healthcare professionals constructed medicines taking practices for patients on an individual basis. In the quote below, the patient negotiated his expectations of prescribers (taking blood to dose medication) with lay knowledge printed in national newspapers,

*"I'd read an article either in the Observer or the Guardian saying there was this big debate thinking that a lot of people were on too much of a high dose and... the next*

*thing, I got a letter from the, the GP saying they were reassessing all the medications... and they reduced it by half. Now that does, I thought they haven't taken any blood or anything..." P5, gout*

The interpretation of interactions between two domains of wider society (embodied here as lay knowledge in the media and expert knowledge from the GP) constructs socially normalised 'ways of using medicines', in this case, contradicting the patient's expectation to have a blood test before medicines were altered.

Through these extracts, it is possible to describe how adherence is experienced; as a construction of given beliefs and cultural values internalised through social interaction with knowledge from wider society and contemporary culture. Knowledge constructed from interaction with others, indicates notions of 'this is how you adhere' within micro-social and macro-social spheres. It appeared that whilst some interactions with wider society were described as given, interactions with other elements of wider society, such as healthcare professionals (as an embodiment of accepted expert knowledge, government policies and 'them'), also fed into how adherence was experienced.

### **Interaction with healthcare professionals**

Exposure to expert knowledge was often reported as an interaction with healthcare professionals. Participants described learning from healthcare professionals, that medicines could be used in particular ways and were 'a necessity', as shown in the quote below,

*"It's just another way... it's either I'm taking less or more, just so that they can keep me... you know... I want to say fit and healthy but I'm hardly... you know... if they keep me going so to speak... if they say take it, I take it, if they say don't then I don't... it's fair enough" P12, cardiovascular disease*

A long extract from a patient with diabetes demonstrates how interaction with healthcare professionals constructs medicines taking practices, that may reflect social practices, rather than objective reality,

*"they took me off a cholesterol tablet, because I was on two and they took me off one, don't ask me what it was [Dr's Name] was the one to ask for that, because he's had a couple of heart attacks, er but nothing else erm, no there was a couple of years ago they said to go back onto the diabetic tablets, metformin. Erm, as well as the insulin, er, and I was put on... a thousand milligrams a day, in one dose, er,*

*which I was taking, and it was [Dr's Name] who said, who the hell had put you on [that], I said hospital he said 'I don't think you should take a thousand in one dose', I said 'righteoo I'll do as you say [Dr's Name]', which is what I do, I take two on a morning and two in the afternoon, they're suppose to lower the sugar level, I always remember [Dr's Name] saying 'they're supposed to lower your sugar level but we'll take that with a pinch of salt with you', I've come to the conclusion there are no two diabetics alike, erm, I think the older you get, cause I've been diabetic now for thirty odd years, I'm lucky, I do know most of the time when my sugar level is getting dangerously low...[...]...and I was getting aerated and I sat down and I thought er, get the glucogel out, he [Participant's Companion] said 'come here I'll take your blood' it was two point four, he said 'you had a good breakfast' and I said 'its nothing to go by with me' and it's not (underlined as the participant shouted this part)" P15, diabetes*

In this quote from P15, it is clear that the participant's experience of adherence to their medicine is fundamentally structured around interaction with his general practitioner, who was also a family friend. It appears that the participant constructs his own understanding of adherence in diabetes, that there are 'norms' which do not apply to him and as a result his medicines use is personalised to how he experiences symptoms of hypoglycaemia. He described the 'cholesterol tablet' and the 'diabetic tablet, metformin' as recognisably different entities, and goes on to describe his adherence to metformin. He explains that his GP, and friend, challenged the dose prescribed by the hospital prescriber, 'a thousand milligrams in one dose' and how he personalised the prescription to 'two on a morning and two on an evening'. From a social science perspective, it is clear the prescription exists as an interaction between the prescriber, the patient and the product. From a healthcare professional perspective, particularly a pharmacist's perspective, metformin is available as 500mg and 850mg tablets, for the patient to take two on a morning and two on an afternoon, he would at least be taking the same dose as the hospital prescriber had initially prescribed. Additionally, in the transcript, a note was made that the participant was pointing to 500mg metformin tablets [extract in Appendix D]. This suggests the participant was taking the same amount of metformin, despite supposed prescription changes. Here the prescription of a medicine and the experience of adherence to that prescription appears socially constructed, rather than reflecting the objective reality of the prescription, as quantified doses of physical products. The participant describes 'taking' the same

amount of metformin as different because it had been prescribed by his general practitioner rather than the different hospital prescriber.

Using this quote it is possible to describe the patient's understanding of the necessity of a medicine as constructed during a social interaction with his general practitioner – 'these supposedly lower the sugar level', but that his adherence was also formed from interactions with the product, with biometric measures and with his physical symptoms, such as when he describes needing to use glucogel when he felt his blood sugar was too low, which was confirmed with a biometric test. The patient's experience of the symptoms of diabetes centred on his understanding of 'what to do' when he experienced these symptoms, which had been constructed from interaction with general practitioner and through his own previous experience of using the product and the product's capacity and efficacy at relieving his symptoms and improving blood sugar biometrics. Additionally his companion also reinforced his behaviour by offering to measure his blood sugar levels. In essence then, the structure of this patient's experience appeared to be informed by a set of rules of how to behave in a given situation, constructed from interaction with his healthcare professional, his companion, and the medicines themselves. This was also demonstrated by P10 in relation to social rules,

*"They say the target is, two to three, if you're within that scale they're happy" P10, diabetes*

Participants describe interaction with healthcare professionals that reinforces adherence through the acceptance of a belief system that identifies medicines as 'needed' within defined situations, such as being diagnosed with diabetes, prescribed treatments or having biometrics within defined scales. Beliefs about adherence also appeared to be constructed from social interaction, when P6 describes the 'reaction' of the chemist to the patient running out of medicines. The chemist is described as 'going out of his way to help' and latently suggests that non-adherence is something that is not acceptable or 'okay' in their view. In essence, the participant describes a social interaction that constructs adherence as essential, that 'medicines shouldn't be run out of', they should be taken as prescribed.

*"I think the whole thing is all connected with the kind of, kind of stabling everything, which they've done, the treatment I've got, in fact I wrote a letter after the mini-stroke last year to the head of the hospital to say how pleased I was with the treatment I got after the stroke, generally speaking the treatment I've got is second*

*to none, including the chemist fella, who goes out of his way to help, if you run out of something” P6, diabetes*

*“I guess I just put my faith in him, I have questioned once or twice cause now it’s into like four or five years, prior to that even... I must confess I wasn’t a good pill taker, I mean if I got a course of fourteen day penicillin or whatever it was I probably lasted about three days and the same with everything else, I never, ever ran the course and I used to be a bit of a twerp” P9, cardiovascular disease*

Interactions with healthcare professionals seemed to alter P9’s beliefs towards adherence, describing himself as behaving like a ‘twerp’ in relation to previous episodes of non-adherence after interactions with his healthcare professional that saw him question the need for adherence. The negativity associated with non-adherence here infers that adherence to prescribed medicines confers positive, desirable attributes; that non-adherence is not desirable.

### **Challenging macro-social beliefs**

Despite the construction of non-adherence as a negative phenomenon, continued macro-social interaction generated medicines taking practices and beliefs that questioned intentions of healthcare professionals,

*“there is an element that if people are trying to sell you their idea aren’t they? Like the doctor wants you to take it so that you don’t get ill and go back isn’t it, so they want you to take it and the chemists they want you to take it because that’s their money isn’t it? So they all want you to believe that they’re right and buy into what they believe, and I mean, although if you were in a car crash or whatever you’d want to go to A&E there is an element that you’re, you know, taking their idea about what’s right and wrong and coffee is bad and chocolate is bad but actually you know coffee is good and it’s even nicer with chocolate [laughing] and it’s the same with the pills they say this is good but actually until you take it you don’t know? And if the side effects are bad then you know it’s just their belief, it’s not always right for you is it” P39, cancer*

This enabled participants to construct their own medicines taking practices, negotiating their physical and micro-social interactions with the product with wider societal practices about medicines uses. In the quote below, a participant with diabetes describes that whilst society (embodied as expertise from the consultant) believes glycerol trinitrate is needed

to treat angina pain, for him, glycerol trinitrate acted to give him a headache, his own medicines taking practices (and adherence) then, represents a negotiation of macro and micro-social interaction.

*“I’ve got diabetes and because of that I don’t get angina pain the nerves have all gone wrong by the heart, so, I remember having a long discussion with the consultant about this and erm.. so.. if I get an angina attack I don’t have any pain, so why the hell should I want to give myself a splitting headache? Because that is exactly what it does it gives you a splitting headache” P3, diabetes*

These inferences were challenged when physical symptoms or measurements did not change, however that expert knowledge, enacted through healthcare professionals, positions medicines as ‘needed’. This constructs the medicine, and medicines generally, as needed in the patient’s mind, generating fear, and leading to modified micro-social interactions between the patient and pharmaceutical products,

*“all they keep saying to you when you don’t take them is well you know you’re at a high risk of having a stroke or a heart attack or, but are you? I mean my blood pressure according to them has been very high, for about six months now, and I’m still fine [laughing] I still feel okay, so is it just a fallacy, am I taking all the pills for nothing... I think that’s why I take just the odd one, because as I say I am frightened it comes back and it’s an awful pain, so maybe if that works, maybe they all work” P20, gout*

In these quotes above, the construction of a medicine’s identity appears to be located around necessity. In P20’s case, despite her gout not being directly related to her survival, and her continued absence of symptoms reinforced her beliefs about the necessity of her gout medicine, and other medicines that had been prescribed for her.

Whilst some participants described challenging interactions with healthcare professionals, some participants described interactions with policy as informing their medicines taking practicing.

### **Interactions with wider society through policy**

Participants reported the construction of the necessity of adherence through the process of obtaining medicines (which is ultimately determined by policy), that medicines were only available from healthcare professionals in response to symptoms of illness, constructed

medicines as objects of necessity and medicines use as based on beliefs about necessity. Whilst there was an acknowledgment that the act of consuming medicines was an individual's choice, the necessity of medicines was inferred from the act of supplying medicines by experts within society, embodied below as 'them', that society provides medicines in response to necessity, constructs necessity when medicines are provided,

*"I don't think they give you these tablets unless you need them... and if you stop taking them then you're putting your life back at risk, therefore if anything happens then you're putting your life back in risk, it's the individual person... it's up to them, you can't twist their arms and put it down their throats, I don't think they would give you them if you didn't need them" P7, cardiovascular disease*

That patients experience a physical symptom, seek care and are given medicine, symbolically imbues pharmaceuticals with necessity, a reason for being. The necessity of medicines was also constructed more explicitly, through discussion with healthcare professionals who are directed by policy to ensure patients understand the necessity of using their medication, described by P28.

*"I was talking to one or two of the nurses and one or two other people, they said when you've got a heart problem I think simvastatin actually is, is, is a must, or there is a good reason that you'd actually want them" P28, cardiovascular disease*

Further inferences were made regarding the necessity of the medicine on a macro-social level in that society supplies medicines, and that harmful products would be kept away from patients through policy, or the good intentions of healthcare professionals,

*"they must be doing some good, otherwise they wouldn't give you them" P20, gout*

Across disease states policy that directs medicines to be supplied only to patients that are ill, constructed medicines-taking practices as a necessity for survival,

*"no it's just because the doctor tells you to take them, I mean they don't give you tablets for nothing, put it this way, why go and see somebody for them to say you are ill you must take these tablets, you must take them for the rest of your life and that's what he's told me I must take these tablets for the rest of me life he says if he don't, say if I left them alone for a week, I'd be probably dead. Because otherwise, why've you got them." P18, chronic obstructive pulmonary disease*

## **Macro-social interactions and the patient's identity**

Adherence and medicines use also reflected patients' perceptions of themselves within society, this links back to earlier findings relating to adherence as desirable, and non-adherence as not desirable. In the quote below, the participant describes herself as implicitly adherent, as a 'normal' member of society that follows social rules when supplied medicines,

*"[If I had been prescribed a medicine before] I would have simply taken them because that's what you do" P41, cancer*

This experience was reflected by participants across disease groups, echoing experiences of adherence as part-and-parcel of being part of society, of their identity within wider social groups (such as being old or ill), such as P17 who remarked about the widespread use of statins,

*"everybody takes simvastatin these days, when you're my age [laughing] I don't know a single person who doesn't take it" P17, cardiovascular disease*

This reflection of wider social beliefs on participants' own identities further infers that adherence represents a phenomenon of social interaction. Here P30 refers to people that use medicines regularly as 'tablet people',

*"P30: generally we're not tablet people*

*[Interviewer: What do you mean by that?]*

*P30: No, well you know like, some people if they've got an headache you know straight away they take a tablet for an headache where as we would sort of put up with that, unless it was really severe, and then you've got to take them, but for a little niggly you wouldn't just sort of take them willy-nilly, it'd have to be really....  
Yeah,*

*[Interviewer: So do you feel like you are a 'tablet person' now?]*

*P30's Wife: Well yes really, we are*

*P30: We can't do without them,*

*P30's Wife: I mean if we could do without them we would,*

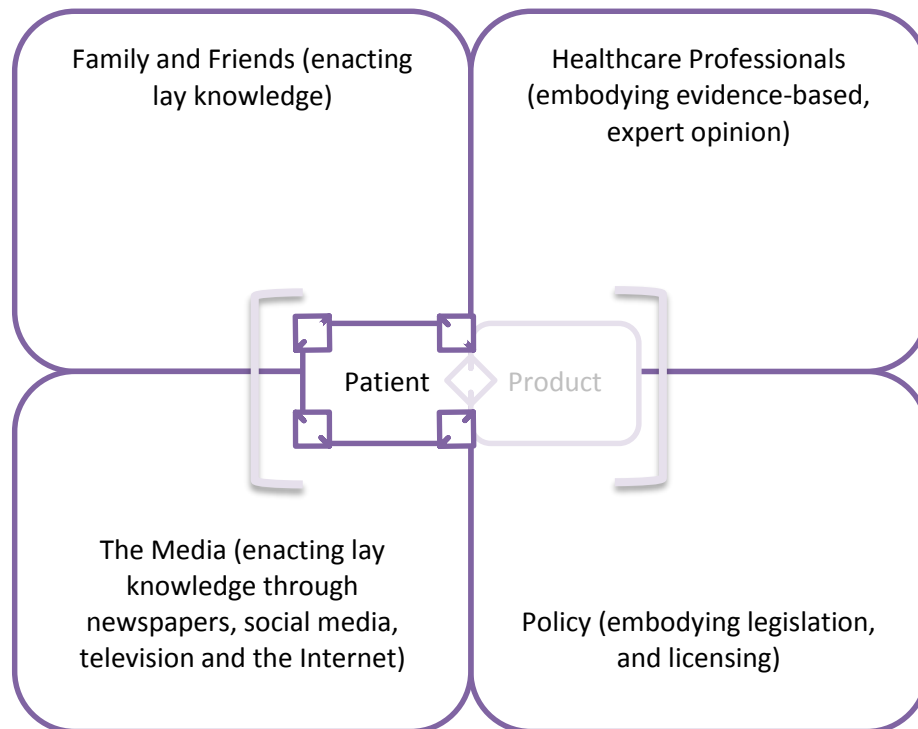
*P30: We would by all means*

*P30's Wife: But if we don't take them, then we'd die quicker" P30, gout*

In this quote it is possible to delineate the meanings that using medicines, and consequently adherence, can infer on a person within the context of wider society. An essential structure of the adherence experience then, appears to be linked to wider social interactions, which goes towards building participants' perceptions of medicines and thus the experience of adherence. As in the previous chapter participants' experiences of adherence was described as a micro-social interaction between the personified identity (encompassing its necessity and propensity to continue working despite non-adherence) of the product and the patient, here the experience of adherence can be described as a macro-social interaction between the patient and wider societal practices and beliefs about medicines.

### **Interpretation and discussion**

This chapter has argued that adherence practices are constructed through interaction with wider society, enacted as lay knowledge embodied by friends, family, the media and the Internet and expert knowledge embodied by healthcare professionals and policy. This chapter builds on the previous chapter, which described patients' experiences of adherence as a phenomenon of micro-social interaction between patients and personified products. A social perspective of adherence is pushed further by this chapter, as it highlights the wider social environment within which micro-social interactions between products and patients take place. This is represented more simply in Figure 9, overleaf.



**Figure 8. Macro-social interaction between the patient and wider society**

Figure 9 simplifies the findings outlined in this chapter. In this figure it is possible to situate, more clearly, the habitual, micro-social interactions described in the previous chapter, within a macro-social interaction with wider society described in this chapter. Macro-social interaction here is constructed by and constructs medicines-taking norms, which feed into patients' identities such as 'tablet takers' or 'tablet people'. This figure does not seek to represent another model of adherence, but rather describes the experience of adherence outlined in this chapter and the previous chapter, as a phenomenon of interaction between patients and products, framed by interactions with wider society.

Whilst this work speaks to sociological concepts of interactions, alternative sociological approaches may be used to interpret the findings, such as functionalism. Adopting a functionalist approach to adherence (Berger and Luckmann, 1966, Berger, 1963), a manifest function of adherence at a micro-level could be interpreted to be to treat symptoms of disease and maintain everyday life, more latently however, at the macro-social level, adherence could be taken to be about fulfilling social norms within wider society, behaving like 'a good patient'. In interviews participants described their experiences of macro-social adherence, as a given, i.e. it is what 'people do' as part of their

life within wider society, to fulfil social roles, to maintain their identity and integrity within society and reach normalised aims. This lens opens up further avenues of adherence research, as to how the phenomenon is situated through sociological, as oppose to biomedical, approaches (Mooney et al., 2007).

The findings of this study align more closely to symbolic interactionism, a theory outlined by Thomas (Thomas and Thomas, 1928, Thomas and Evanston, 1967) that describes the importance of subjective perceptions of objects or concepts that 'define situations' and construct behaviour. The approach postulates that subjective perceptions are generated from interaction with others and that this leads to particular behaviours or actions. A prior example of this within pharmacy might be the placebo effect, as a product is prescribed and supplied, other people (as embodiments of society) are acting as if the product will do something, will act in a particular way or perform certain behaviour. This constructs perceptions that the product will act, despite scientific evidence arguing the contrary. Symbolic interactionism argues that perceptions, beliefs and meanings are constructed from social interaction.

As patients interact with multiple actors within society, embodied as friends and family, healthcare professionals or social media, their beliefs and perceptions about medicines are constructed, generating personified product identities – adding subjective value and meaning as per Thomas's theorem. Where the findings of this study vary from the theory is when personified products are transformed into social actors, and begin to define situations when medication is needed and not, as outlined above as episodic short-term non-adherence. The findings realign with the theory as interactions with wider society also feed into patients' beliefs about when medication is needed and not needed. These interactions feed into patients' beliefs about their identity, described as 'self-concept', gradually constructing a personal, internal set of beliefs, practices or philosophy that frames their experience of adherence within the context of wider society and how others might see them. That the findings of this study can be located with the theory of symbolic interactionism represents a novel description of how patients experience adherence.

One of the strengths of symbolic interactionism is that it provides insights into micro-social interactions, which can be explained as functions of subjective beliefs, explaining why objective situations can be interpreted and defined differently by different people. Equally this theory enables micro-social interactions to be considered within the context of wider social norms and wider social meanings that might be attached to particular behaviours or

objects. However, this theory does not necessarily account for the broader policy influences that were reported by patients, which are embodied by legislation (at least in this country) that governs the accessibility and availability of medicines. This suggests additional work may be needed to explore the role of policy and the construction of wider societal medicines taking practices. A draw back of the application of this theory may be the intrinsically subjective nature of the construction of meaning, which may prevent quantification of patient interpretations and personification of their medicines, thereby, potentially limiting the ability to test the theory using more conventional biomedical approaches.

## **Conclusion**

This chapter has outlined findings that described how patients experience adherence. Highlighting the importance of interactions with lay knowledge, enacted through friends, family, the television, the Internet and the media, and expert knowledge, enacted through healthcare professionals, policy and legislation.

That medicines use was described as constructed through interaction with wider society locates the adherence phenomenon within a social sphere. The adoption of a sociological lens lends itself well to exploring the adherence phenomenon a new, enabling a novel description to be made and insights gained into patients' experiences of medicines use. Understanding the adherence phenomenon from this novel perspective provides a structure for further work, which will locate patients' perspectives of current adherence interventions within patients' experiences of adherence, forming new directions for intervention development, as outline in the next chapter.

## Chapter 6: Interactions with interventions

This project used focus groups to collect data on participants' perspectives of adherence interventions. This data was used to validate the findings outlined in previous chapters as well as concentrate more directly on interventions within patients' experiences of medicines adherence. Focus groups were carried out in accordance with the schedule in Appendix B. Outlining different adherence interventions that appeared in the interview data and in the literature focused the discussion, with participants given an opportunity to describe any additional adherence interventions they were aware of. In the focus groups, participants described their experiences of interactions with a range of different adherence interventions. The analysis of this data is outlined below.

### Interactions with interventions

Throughout the focus groups, participants described interventions as objects of necessity. Participants often described interventions as 'not being needed, just yet.' For example, in relation to reminder devices, participants appeared to conceptualise these devices as being reserved for the elderly or the more seriously sick. This seemed to posit reminder devices as objects of necessity, in a similar way to the medicines themselves. Within this theme, interventions were often described negatively across all three focus groups,

*"Facilitator: You mentioned that you worry how old people would get them out, do you associate adherence devices with older people?"*

*P5: that's who they're made for yeah*

*P4: age yeah" Focus Group 1*

There appeared to be a link between intervention use and cognitive deterioration associated with old age,

*"P3: I think we at the moment, we're reasonably compus mentus, I think it's the ones that are starting with the Alzheimer's that really do need assistance on that kind of thing, and some of the things you've raised there about reminder alarms and that sort of thing, I think may be useful for a portion but I don't need that quite yet, perhaps as I go on I may" Focus Group 2*

This constructed the need for an intervention as being undesirable, detached from 'appropriate' medicines taking practices,

*"P3: no. I've set them up for other patients but no I'm not too bothered about meself, I've got a perfectly good packet that tells you what to do, if you write it in red on it then you'll remember [P2: laughing] if you start forgetting taking things then you seriously are off*

*P2: [laughing]" Focus Group 3*

The quote below refers to a reminder device, GlowCap, that reminds patients about their medication through audio-visual cues,

*"P2: it's [Glowcap] good if you're struggling to remind [sic], all the time, if you're getting old and you do need reminded it would be good for that I think*

*P6: not for me*

*P5: I wouldn't use them*

*P2: when you're older" Focus Group 1*

Interventions seemed to be something that was inevitable with increasing use of medicines, something that all of the participants were working towards, eventually, needing some sort of support to adhere to their medication,

*"P1: that's not necessary I only take one tablet a day. I can see the sense of it, my mother used to, she had hundreds erm, she eventually graduated to one of those and as she started losing her memory as well it was really, canny useful but it just seems eminently sensible and logical to me, but it's just not necessary for me at the moment" Focus Group 3*

The appropriateness of interventions appeared to be intrinsically linked to society's conceptualisation of adherence and 'ways of taking medicines', with more technological interventions, such as electronic reminder devices and silicone chips, considered more appropriate for the 'tech-savvy next generation',

*"P1: but really in about fifty years time, that watch thing will work, because the people that are coming up with that technology now will live by it and those of us that didn't live by it prefer human interaction and these kind of things, so maybe for*

*the future but it's some time off for me, until I want to rely on that I would still rather do it on bits of paper even though I have a computer and a telephone" Focus Group 3*

This quote highlights the social nature of adherence and adherence interventions to wider society within contemporary cultural practices. What appears to be clear from these findings is a conceptualisation that adherence interventions are for someone else; either the elderly, the very sick, those on patients multiple medicines, or the next generation of technophiles, an indication that adherence interventions are products and services for not just someone else, but anyone else. This suggests that interventions are representations of failure with these ideas, seemingly, constructed from social interaction with others that had used these interventions.

*"P2: yes I can visualise a time when I might, possibly, want it but certainly not now*

*P3: well you've got this far you wont need one" Focus Group 3*

In this sense, interventions were not described as different between participants with different illnesses, but rather participants seemed to describe interventions as having social capital, as representations of negative necessity, of an inability to use medicines as they should be used. As with the medicinal products themselves, the necessity of using an intervention appeared to be constructed of beliefs associated with survival,

*"P2: no, no, no, nope, I've got a little thing up there, Monday, Tuesday, Wednesday, Thursday I use and it's just part of my life now and the main aim of the goal is to keep this side of the grass [laughing] if you know what I mean. The other side is worse [laughing]" Focus Group 2*

Participants also described their experiences with specific interventions. These experiences are grouped thematically and described below.

### **Educational Interventions, including patient information leaflets**

Participants often reported educational interventions positively; although the patient information leaflet was often spoke about negatively. Educational interventions that were discussed included services delivered by pharmacists, doctors and nurses as well as 'reading up about the medicine'.

*“P7: oh you mean when you go and sit with the chemist? Yeah we get called in for that all the time, now and again*

*P3: yeah he wants to know what I’m taking and how I’m taking it, what for*

*Facilitator: what was that like? Did it make you use them as they were prescribed more?*

*P7: oh no, he was just checking up on us to make sure we take them” Focus Group 1*

More simplified information was sought, particularly about what the medication was for and how it should be taken. A particular example of this was during interactions with healthcare professionals or medicines information that directed participants to use medicines in particular ways,

*“P2: can I go back to the grapefruit thing because it does say on the thing, do not take this medication with grapefruit, now I could read that in two different ways like don’t take your tablets with grapefruit juice at breakfast but you could take your tablets at night when you’re not having your grapefruit or does it mean you must eliminate grapefruit from your diet full stop?*

*P3: well our pharmacist said any fruit juice really*

*P2: yes, well he said swallow it with water*

*P3: for that particular medication anyway*

*P2: yeah, and of course a lot of pain killers, don’t drink alcohol and does that mean at all, or just to wash it down, but I would imagine you wouldn’t drink it to wash it down with but is it not at all so in the morning you took your pain killers and then you can’t have a drink in the evening. Well I just took it that I’m not having alcohol at all and I said this to him, a retired surgeon friend, he said ‘are you having a drink?’ and I said ‘no I’m on these pills and I mustn’t drink alcohol’ and he said, ‘oh’ he said ‘ditch the pills’ [laughing]” Focus Group 2*

This was also related to biometric measurements that had been shared by physicians, whereby one participant related their experience of forgetting to take metformin on an evening resulted in a ‘high measurement’ from her doctor, which prompted her to take her medication more regularly.

*“P6: well I did, and I’ll tell you why for why [sic], I wasn’t taking the two on a night, I kept forgetting to take me two metformin on a night and when I went for my check up it was high, I don’t know what was high, but it was high, and I thought ‘it’s because I haven’t been taking it on a night’ since then I have been taking it properly like” Focus Group 1*

Participants also discussed using multi-compartment compliance aids as an interaction with their medicines that was aimed at improving adherence.

### **Multi-compartment compliance aids, including pillboxes**

One of the key findings in relation to MCCAs was that different participants described or named them in different ways (none of which included MCCAs). Participants used a range of labels for these interventions, including ‘dosette boxes’, ‘medipacks’, ‘packets’, ‘NOMADS’, ‘trays’, even ‘one of those Monday, Tuesday, Wednesday, Friday, things’. A participant that used an MCCA without knowing how to name it demonstrates this phenomenon in the quote below,

*“P7: you can have a packet can’t you*

*P1: yeah a medipack*

*P7: oh is that what they call it*

*P3: everybody should use them containers, with the erm Monday to Friday thing on”*

*Focus Group 1*

MCCAs were described as generally positive, both in relation to accessing medicines by preventing issues with ‘popping’ medication out of manufacturer-supplied packaging and confirming if medication had been taken.

*“P1: yeah. And like for old people on the back it’s quite difficult to snap them, you know*

*P7: yeah it can be quite difficult*

*P6: aspirin are the worst*

*P1: well I think, for our mam, how the hell would she manage with that*

*P7: my husband sometimes struggles with that*

*P1: when you're trying to pop them out" Focus Group 1*

This quote demonstrates perceived difficulty of opening some medication and the use of MCCAs by older people. This quote also demonstrates that these difficulties associated with packaging feed into patients' beliefs about the medicines identity, here P6 states 'aspirin is the worst', which was reiterated by a different participant in a different focus group. Part of the constructed identity of aspirin then appears to include difficulty in opening the product. Repackaging products into MCCAs did not always resolve difficulties opening medicines;

*"P3: could I just make a point about getting the pills out of the little trays, I've got one at the moment which is really, really difficult. It's got very thick plastic on one side and aluminium I think on the other side but I have real trouble getting one particular one out*

*P2: yup yup*

*P4: particularly aspirin for me" Focus Group 2*

Participants also referred to medicines' identities further, in relation to the medication's ability to be re-packaged. Participants raised concerns about the integrity of the dosage forms when medication was stored outside of its manufacturer-supplied packaging, recalling information from pharmacists and patient information leaflets that described medicines 'breaking down' if not stored in the original container. One participant related this to 'a packaging system', which was 'conditioning the tablet' – this was most often recalled by participants that had chosen not to use an MCCA.

*"P1: well what one of the pharmacists said to me before was, how do you know, if you're opening your tablets prior to that, do they have the same effect because you've took them out of the blister,*

*P4: oh right*

*P1: yeah because they've been opened*

*P5: like if it's dissolvable? Any damp bits would get in it and a bit might fall off*

*P4: oh right, I get it*

*P2: so does that happen to the other tablets? It might weaken them” Focus Group 1*

Here it is possible to see how the repackaging of products feeds in to the construction of medicines’ identities, as products become known to be able to be repackaged or not as patients ‘get to know’ the medicine through interaction not only with the medicine, but with wider society, embodied above as the pharmacist.

In relation to how patients interacted with medicines micro-socially, these devices, rather than reminding patients to use medicines in the present, appeared to be more beneficial as reminders that medicines had been taken retrospectively.

*“P2: [...] I take three things, erm, but none of them for anything very serious but it has become part routine, I have two of them on the breakfast table, and I have one of those boxes with the days of the week, I would certainly forget what one had been taken if I hadn’t...[Facilitator: what made you start using one?] P2: well simply the difficulty of remembering to take them and knowing whether I’d taken them or not. I mean none of them are sort of, life threatening, or life preserving particularly but erm, erm... they’re actually for erm, that particular one is an anticoagulant, prophylactic, in case I were to get a clot, but er, yeah” Focus Group 3*

Re-packaging medicines was not considered helpful when non-adherence was due to changes in routine that involved leaving the house, this was often related to devices that were large or cumbersome, and could not be transported easily or were medication needed to be administered by a third party (such as a carer at a day centre) at a later time,

*“P2: yes and the other problem with adherence is if the patient goes to a day centre, so many days a week. The day centre are supposed to administer the medication, perhaps at lunch time, but the patient comes with a pill, in a little bag, haven’t a clue what they are, or who they’re for and it’s really confusing. I mean it’s alright, like he says, if you’re at home. But when you’re out of the house, it’s just a nightmare.” Focus Group 2*

Some devices could be broken down, to enable smaller compartments to be taken with patient as part of their daily routines, however this did not appear to facilitate better adherence.

*“P3: well I’ve found them very helpful, I couldn’t have managed without one, about twice a week I fill them up although actually it seems to come round about every*

*other day and that's the way I'm measuring the passage of time. But yes it shows, there you can take an individual cell out and pop it in the pocket and get away with taking it if you're going out for a meal or out for the day, often again, I couldn't take that enormous great box out there so yes they're very helpful but there again there are times when I've still got this rattle-y old pill in the cell in the lunchtime so it's not infallible." Focus Group 2*

Participants reported filling MCCAs positively, as an interaction that generated familiarity with supply levels,

*"P1: [...] about once a week she does her counting out and if she finds that she is running out of a particular tablet she then knows to re-order it*

*P2: that's right*

*P6: yes that is the benefit of them" Focus Group 2*

Medication reminder charts were considered to be 'just like the' MCCA and charts that required participants to tick or sign to indicate medicines had been taken were described as 'too much of a faff'. Outlined by one participant below,

*"P5: and think oh I'm not going all the way there to tick that, that'll be why you don't do it, I mean I think these things are all alright and it's easy enough to do them we could sit down here and do them all alright but that's not life, in life you're all over the place and you need something that will fit in with that" Focus Group 2*

## **Reminder Devices**

Reminder devices were overwhelmingly associated with 'being old, 'Alzheimer's Disease' and being on serious medication. Participants described these devices negatively, as something that they did not want to use or have to use.

*"P2: it's good if you're struggling to remind, all the time, if you're getting old and you do need reminded it would be good for that I think" Focus Group 1*

*"P1: I'd need to think about it, and as I say, where I am at the moment I don't need it, if I got into a position where I would need it but at the minute I've got a lot of alarms coming out of my ears with this thing [mobile phone], my radio alarm and er, house alarm, burglar alarm and smoke alarm – I've got too many alarms going off and I can just imagine something like that, if it was just left, if my alarm were by*

*the side of the bed, and I'd left it there, I wouldn't want to carry it around with me, and I wouldn't necessarily hear it, so I'm not convinced unless you're housebound or something, urm, at the moment I certainly wouldn't need them, at all*

*P2: I would agree with all of that I think*

*P3: well I would no, I will rely on my brain otherwise I'm going to get Alzheimer's even more quickly" Focus Group 3*

These devices were considered only useful for people that stayed at home, as an embodiment of a micro-social interaction between the patient and the product. One participant highlighted what would happen if a reminder device sounded, but someone did not have their medication with them and the anxiety this would produce.

*"P3: you'd have to have it with you all the time for when it goes off wouldn't you?*

*P5: it's a good idea but it's a waste of money cause it's not going to help you take them*

*[...]*

*P3: so you get it, and it's been set up for you by the chemist, you're down the town and it goes off*

*P6: what're you gonna do, you haven't got your tablets with you?*

*P5: oh shit I'd never thought of that" Focus Group 1*

Two participants in separate focus groups expressed views that poor memory, which would make these devices necessary, might lead to users of these devices not being able to remember what they were being reminded about,

*"P1: this flashing thing is just, you know, if you're starting to lose you memory that you've taken stuff then you'll just be thinking what the hell is it flashing for all the time*

*P3: yes that's right*

*P1: so I think, my personal, I've got a start position that I don't actually need it anyway at the moment so as, exactly as you've said P3 in the future, who knows where I am going to be, but the point is we're trying to get very, very scientific and*

*controlled and I actually don't like that control, I like support, I don't like control and that's what that is*

*P2: well I use the timer in the kitchen when I'm cooking and I often can't remember, when it goes off I have to think what it is that's why I set it [laughing] [laughing]*

*P1: that's exactly*

*P3: it adds to the fun of old age [laughing]" Focus Group 3*

Participants also reported concerns about becoming dependant on reminder technologies and what happens should the technology fail. Others highlighted concerns about airport scanners or other devices might cause interference with reminder devices, incorporating a macro-social element of everyday interaction on intervention use.

*"P1: two things concern me are what happens when it fails, when you come completely dependant on it, I mean I've been struggling for the last ten days without my laptop and having to log in through other and the number of things I've got set up to make things easy and it, it's nearly driven me round the bend trying to find stuff on other systems and secondly, anything electronic you don't always realise you've made a mistake and if you've had to do any setting up yourself, and if you don't understand it, and you're living on your own, in other words you haven't got your grandchildren round to help you, erm, who is going to hold your hand to take you through it? Erm, now that might be relatively straightforward to set up, but I still wouldn't like to rely on it completely. On the other hand, if I were, maybe in a few years time, maybe I would be getting forgetful more times than that would work" Focus Group 2*

All three focus groups remarked on the expectedly high cost associated with these devices, although conspicuous by its absence was who would pay for these devices (the participants themselves, the healthcare services or someone else).

*"P3: how much do they cost a piece?*

*P2: [laughing]*

*[...]*

*P5: it sounds alright but it would drive them mad [laughing]*

*P3: well it's like those iWatches isn't it it'll cost a fortune " Focus Group 2*

Another intervention that was mentioned briefly, and tied into using reminder devices, was collecting information about 'how adherent' a participant had been, to highlight to the participant their own medication-taking behaviours, which they might not be consciously aware of. This was described as being particularly beneficial to highlight cases of over-use, which would prompt participants to review their medication use.

*"P5: so I suppose it would show you how much you've taken like 80% or less or whatever as well as read your pulse*

*P1: and probably your blood pressure and everything*

*P4: he wants one! Do you think knowing how much you'd taken will make you take it properly though?*

*P3: well if it should you were misusing them, like taking too many*

*P7: yeah then you would think oh I'll have to stop" Focus Group 1*

Mobile phone applications were also discussed however participants in all focus groups described elements of technophobia, suggesting that some, more complex technological interventions may be best suited for particular groups of people who are interested in 'gadgets' or the next generation. This draws on the notion that the patient's identity (as a technophobe or technophile) might frame experiences of interventions.

*"P3: there are apps for your phone aren't they, I take it this is something just a stop clock*

*P4: well my son did it, we're not able to do that kind of thing*

*P6: we're technophobic" Focus Group 2*

Participants described concerns about complicated reminder devices needing to be 'set up' by a pharmacist, a doctor or a carer, with some highlighting their own experiences of their children setting up alarms on their mobile phones.

*"P4: my son has now put an alarm on my phone, but the alarm goes off and depending where I am I might not have them with me, or I might just turn the alarm off and carry on doing what I'm doing" Focus Group 2*

This quote describes a macro-social interaction, the reminder that the reminder was 'set-up' by an external actor, that then itself goes on to enact the micro-social interaction between the patient and their product.

### **Peer-Support and Media**

This theme relates to when participants described discussing adherence with others, through a peer-support mechanism or via media, including social media. These experiences describe macro-social interaction that structured the experience of adherence. For example one participant was reminded to take his medication on an evening through the theme tune for the 10 O'clock News followed immediately by a phone call from his wife.

*"P5: I take mine at ten o'clock most nights and I use the ten o'clock news bong, bong, bong, bong [background laughing] then me phone starts ringing and I take me drink a water, answer the phone 'hia, I've took me tablets'" Focus Group 1*

Another participant imagined notices in newspapers that might prompt readers to take medication, tapping into the routine nature with which they themselves read the newspaper. Other participants discussed interaction with others, typically a spouse, that acted as a reminder and one participant described the huge impact of living alone on all routine daily activities,

*"P5: but you've also got your wife to remind you, when you're on your own, it's vastly different and quite honestly until you experience being on your own, nobody knows*

*P3: oh yes yes, she's very good that's right*

*P5: I find a lot of things very difficult now because I'm on my own, you can't rely on anything, but yourself" Focus Group 2*

Interactions with others was discussed in all of the focus groups, with one participant remarking that discussing ways of taking medication with her friends would be a good way to learn about medicines if she could play bingo at the same time, other participants suggested discussing medicines use with friends and family was something they already did, whilst another participant suggested that discussions might take place on social media platforms,

*"P4: I'd only do that if you could play bingo at the same time [laughing]*

*P3: it sounds like group therapy that*

*P7: oh I'd be there*

*P2: well you talk about it at the bingo don't you*

*P4: they do, cause they take the same stuff don't they*

*P5: some people are proud of what they take*

*P7: aye, so and so*

*P2: I think you're talking about me?*

*P5: no not you just some people are very happy to talk about it, put it on Facebook and stuff asking for any extras or offering them away*

*Facilitator: Do you use Facebook, Twitter or other social media to talk about medicines?*

*P2: no cause I don't want people to know what I take*

*P3: I think it's dangerous*

*P4: but you only talk to family about it*

*P7: oh no I've got friends who I talk to" Focus Group 1*

Whilst some participants felt discussing medicines use with peers was acceptable, some participants were not as engaged with this idea, describing it as dangerous and not wanting other people to know what medicines they took. These views reflect the differences in medicines taking practices that were adopted by participants, on the one hand that medicines use was something to be discussed and on the other that medicines use should not be discussed with peers. These differences could be interpreted to represent the subjective nature of the construction of beliefs, values and practices through social interaction that might pre-predicatively construct taboos. Negative views associated with lay knowledge appeared to stem from a lack of credibility and trust of that knowledge, with some participants concerned about other people in the session that might think they know more than they actually do,

*"P3: if you don't select the right people in the group you're not going to get the right people in the group are you? You always get the one or two people who can*

*tell you more than you know and that goes for these online forums, how many people do you know that try and be a doctor by reading what they read on the forums? On Facebook?*

*P2: online*

*P7: they say a little knowledge is dangerous don't they*

*P3: you know what I mean?*

*P4: people were looking online and*

*P2: prescribing themselves of how to take the drug*

*P7: well yeah you see people doing that because of what they've read in the newspapers as well, I think it's dangerous really" Focus Group 1*

Participants also discussed how social media can be used to share medicines illicitly, potentially feeding into participants' negative beliefs about social media and medicines. One participant reported that whilst he believed his medicines taking practices should not be discussed with others, he went on to describe how he offered advice about medicines use to others,

*"P1: oh I don't think so, the only time I have ever discussed my tablets is coming here today, what it's of nobody else's business bar mine [laughing] and it's not a kind of topic of conversation that I would like to have – although saying that occasionally I have said to people that have said they've got gout that I take allopurinol and that it's worked well and then somebody else has said, oh you know I've been into the diagnoses game not that I'm anywhere near a pharmacist or doctors or anything, but if they say they're suffering with this then I say oh bloody hell check with this because it might be gout, and this thing cleared it up for me"*  
*Focus Group 3*

This suggests that the participant had an idea that 'medicines talk' should be restricted to healthcare professionals and patients, however in reality 'medicines talk' was something he himself engaged in with colleagues at work. It is possible to interpret from this extract, that P1 through 'medicines talk' was constructing the social identity of allopurinol, as the pill that 'worked well' for gout, as part of an interaction with wider colleagues.

Indeed increased interaction with others about medicines was also suggested as a way to improve adherence,

*“P4: maybe we should start asking people as a greeting, instead of saying ‘good morning, how are you’ we should just say ‘hello, have you taken your tablets’  
[laughing]*

*ALL: [laughing]*

*P2: ‘what’s the weather like, have you taken your tablets?’*

*P4: that’s right, that’s right” Focus Group 2*

This data suggests that interventions that involved wider interaction with society may be a way to normalise medicines use, as well as normalise self-monitoring of medicines use. Discussion concerning overuse of medicines tied into wider discussions about reducing the amount of medicines prescribed and taken. This led to discussions of an idealised poly pill.

### **Poly pill**

The poly pill or methods that included combining multiple dosage forms into one composite were discussed favourably in all of the focus groups.

*“P4: I think what they should be working on is a device that amalgamates all your tablets, were they grind them up and put them all together in one thing,” Focus Group 2*

Participants described taking just one pill per day as ‘beneficial’ and ‘convenient’, resolving many of their issues with adherence.

*“P3: well I would go with that a poly pill*

*P4: where they make your own individual pill? Yeah*

*P2: yeah I could do with that I think*

*P3: that would be ideal*

*P7: then you’d know what you’ve took cause it would all be in just one*

*P1: that would be ideal*

*P2: then you wouldn’t look like a druggie when you’re taking them all*

*P5: but depending how many you're on it would be the size of an orange wouldn't it*

*P4: they'd be able to make it smaller though surely*

*P5: but that would be expensive*

*P3: but probably less expensive than not taking it and having a heart attack*

*P1: I think a lot of people would prefer that" Focus Group 1*

Changes to the characteristics of the medicine, i.e. its size, were described as a concern, with participants often supposing to have each of their medications in it, it would need to be quite large. Some participants described the poly pill with concern, highlighting the significant cost and limited flexibility in prescribing that would be associated with using such an intervention.

*"P2: I think that's much, much easier, much better but whether it can be done or not is, but I suppose pharmacies could do that, because they're chemists as well aren't they*

*P7: but then what if you wanted to change it halfway through? Or stop taking one but not the other?*

*P5: well they'd just make it again wouldn't they, but you'd have to prove that it worked wouldn't you?*

*P2: well no but then it's which one doesn't agree with you, you wouldn't know"*  
*Focus Group 1*

In these extracts participants describe the poly pill as an accumulation of different medicines' identities, 'which one doesn't agree with you'. One participant argued that the poly pill would have to be shown to 'work', with another participant highlighting her modified-release medicines and another highlighting how nasal sprays and eye drops, might not be able to go into a poly pill. Other participants highlighted that non-adherence would be limited if medicines were supplied in one composite dosage form,

*"P5: you said your omeprazole, you're meant to take two but you take one*

*P4: yeah*

*P5: well if it was made like this*

*P4: well I'd just take it then wouldn't I because it wouldn't be any option?" Focus Group 1*

Other participants raised apprehensions about how their decisions about which medicines to take may be compromised, describing a process of moving onto a poly pill following agreement with prescribers,

*"P3: well I'm just looking on the list up their, metformin, aspirin, statin and an ace inhibitor... well what happens if you don't want to take one of them?"*

*Facilitator: Good point*

*P2: scrape it off*

*P3: well when patients used to say to me that they're taking too many pills, I say to them well the only person who puts the pills in your mouth is yourself. You're the only one person that does it, you can refuse it if you don't want, like I refuse to take statins*

*P1: well yeah but if the three or four are agreed and you want to debate one then keep that one separate for the time being. It's so much more sensible to me, to have one rather than three or six or what have you, and if there is one you don't want to take then just have it taken off"*

Whilst the poly pill was spoken about with much less intensity, it represents an intervention that may change the product's identity as well as the micro-social interaction between the product and the patient. Inferences can be made about the impact this might have on patients' identities, as active decision makers or passive accepters of prescriptions, in terms of their choices about what and how medicines are taken.

## **Discussion and interpretation**

These findings describe participants' perspectives of interventions as variable and dynamic. Whilst there is depth in the descriptive quotes that offer insights into each group of interventions, a key finding here is that interventions are conceptualised as objects of necessity. As other chapters described patients' experiences of constructing personified medicines' identities through micro and macro-social interaction, constructing personified medicines' identities, these findings support previous chapters and suggest that adherence

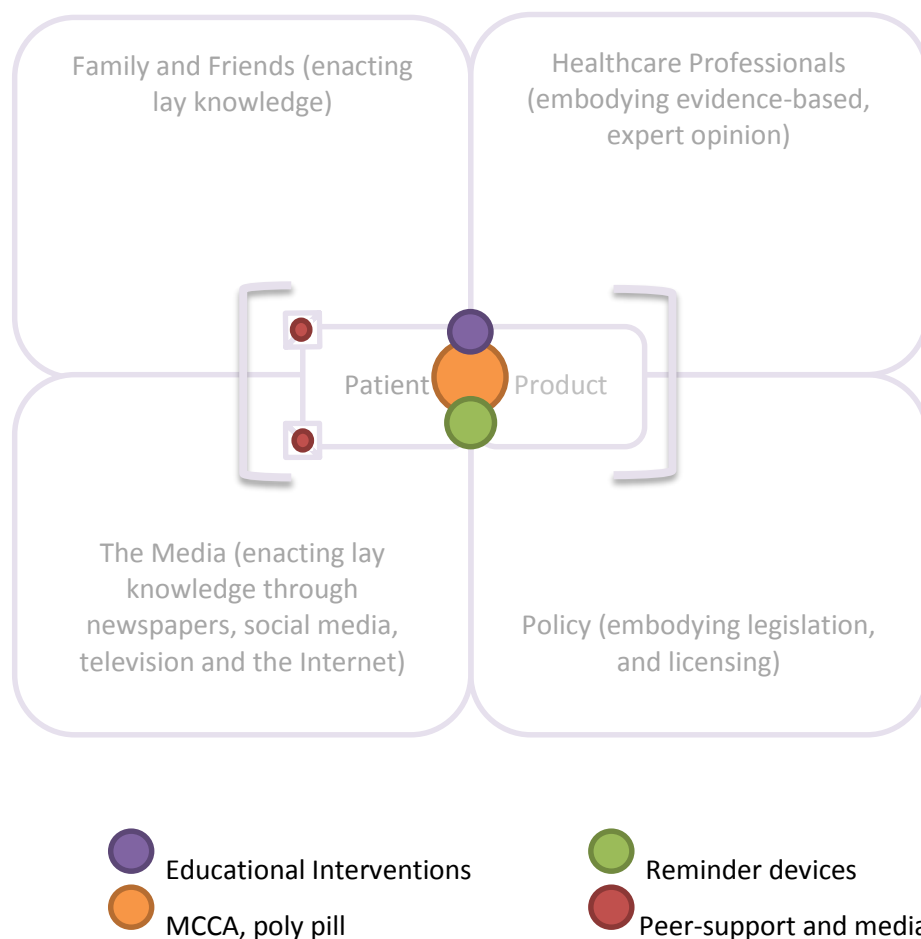
interventions are also imbued with social meaning, representing interactions between products, patients and wider society.

Interventions to support adherence were imbued with meaning, becoming objects that represent an interaction between the patient and society, in a similar way to the construction of beliefs about necessity of medicines use (Horne and Weinman, 1999, Horne et al., 2013, Horne R et al., 2006 , Thomas and Evanston, 1967). That interventions are reserved for the very elderly or the very sick could be interpreted to position adherence to medicines as a behaviour that is desirable, that 'should' be able to be performed as a norm within wider society, feeding into earlier findings that adherence represents a phenomenon of social interaction. Equally, associations between being elderly and being very sick and polypharmacy might enable these perspectives of interventions to be interpreted as part-and-parcel of graduated medicines use, i.e. as patients get older, more medicines are needed and so adherence interventions are needed. These findings enable adherence interventions to be identified as embodiments of interaction, constituting part of constructed medicines' identities or more directly as objects or practices that represent interaction between the product and the patient.

Interventions were described as being part of the micro-social interaction between the patient and the product, becoming part of a product's identity in the form of changes to packaging or dosage forms, as for the poly pill. Interventions in the form of reminder devices represented micro-social interactions between the patient and the product. In essence these interventions *were* micro-social interactions that framed how patients and products interacted with each other to establish routine medicines taking.

These findings also support previous chapters that described patients' experiences of adherence as one of social interaction with wider society. This perspective enables educational interventions to be presented as a representation of an interaction between the patient and wider society, enacted by healthcare professionals who deliver these interventions. The delivery of educational interventions creates an interaction between the patient and expert knowledge supporting a perspective of adherence as a phenomenon of interaction with wider society. The data also highlights a small number of interactions with wider society embodied as peer support and the media. Whilst these experiences were reported less than changes to product packaging and reminder devices, they suggest that medicines use is contextualised to norms and beliefs established by interactions with others.

The location of interventions within a description of adherence underpinned by social interaction is represented in Figure 10 below. A diagrammatic interpretation demonstrates how different interventions embody interactions between the patient, the product and wider society. Interventions that repackage products were described most often by participants and are represented by the largest circle in the figure. These interventions construct the product identity, changing the medicine’s location, physical appearance as well as constructing patient knowledge about where it can be stored. Reminder devices were also discussed frequently by participants and embody interactions directly between the product and patient. Educational interventions represent the third most described intervention and can be located as interactions between the patient and expert knowledge from healthcare professionals. Finally a small number of interventions were described as peer-support and the media represented by the smallest circles in the figure, embodying both interactions with family, friends and the media.



**Figure 9. Adherence interventions within a novel perspective of adherence**

These findings demonstrate that the majority of interventions occupy interactions between the patient and the product, with smaller proportions of interventions representing interaction with wider society. This highlights an area for future intervention development that might seek to expand the number of interventions that embody interactions with lay knowledge enacted through friends, family, and the media. Whilst these findings enable current interventions to be located within a novel description of adherence, they also highlight directions of future intervention development.

## **Conclusion**

This chapter has validated a novel description of adherence that presents medicines use as a phenomenon of micro- and macro-social interaction. This has enabled current interventions to be conceptually located; demonstrate that reminder devices and repackaging products, in MCCAs and pillboxes, represent the most well established 'type' of adherence intervention, thereby locating the majority of current interventions within a micro-social sphere of interaction between the product and the patient. This highlights novel directions for future intervention development, which might be established to embody, enact or exploit the wider social interaction that encapsulates patients' experiences of medicines use. Finally further work is needed to establish if this perspective can be generalised to broader populations.

Chapter 9 seeks to further synthesise and interpret these findings within the context of pharmacy practice, adherence research, and intervention development.

## **Chapter 7: Synthesis and interpretation**

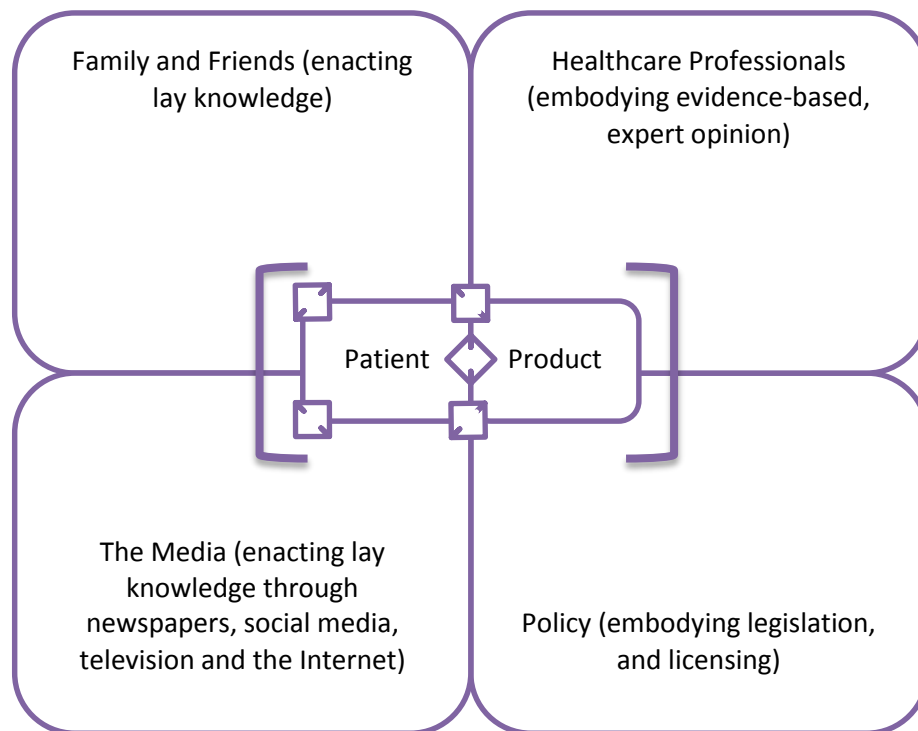
This study set out to describe patients' lived experiences of medicines adherence across a range of diseases, including cardiovascular disease, diabetes mellitus, gout and chronic obstructive pulmonary disease. Understanding lived experiences has contextualised patients' perspectives of interventions, identifying areas for future intervention development. This chapter discusses each of the research questions outlined in the introduction, summarising the findings in relation to the research questions and locating the findings within the context of other research.

### **What are the lived experiences of medicines adherence in adults taking medication in different disease states?**

This thesis describes patients' lived experiences of adherence as a phenomenon of social interaction in a number of different disease states. Previous chapters have outlined that participants in this study experienced adherence as a relationship of necessity within a constructed medicines or product identity. This was experienced through micro-social and macro-social interaction. Participants' perspectives to interventions were described in detail to a number of different intervention types, identifying that adherence interventions were conceptualised by participants as objects of necessity, imbued with social meaning. By synthesising and interpreting these findings it is possible to delineate novel directions for intervention development and ensure patients' experiences of medicines adherence and perspectives of interventions contribute to this process. These findings support the argument that adherence intervention development should be directed towards utilising domains of wider social interaction to improve adherence.

#### ***Adherence as a social phenomenon: a novel perspective***

This work has enabled the essential structures of adherence to be identified, generating a new description of the phenomenon. The findings can be summarised and interpreted using Figure 11 below,



**Figure 10. Adherence as a phenomenon of macro and micro-social interaction**

This figure describes patients' lived experiences of medicines adherence in this study. It represents how patients construct the experience of adherence socially, learning pre-predicatively, without really trying patients are picking up information, prejudices, beliefs and approaches to medicines taking that will come to embody a set of values that add structure to their experiences of adherence as a lived phenomenon. The figure highlights that the micro-social interaction between the patient and the product is encapsulated within macro-social interaction with domains of wider society, identified here as family and friends, the media, policy and healthcare professionals.

A phenomenological description summarises the findings in a way that seeks to help the reader understand the phenomenon better in a concise way;

*The lived experience of adherence is a fundamentally social phenomenon, constructed through social interaction with multiple actors including healthcare professionals, family, friends, the mass media, but also the medicines themselves, as integral social actors in a patient-product-peers-*

*professional-patient interaction that continues throughout the patients' life and the life of the prescribed product.*

Social science research has identified the social meaning of medicines, as symbols of illness that are transformed from inanimate chemical objects to intrinsically social objects (Cohen, 2010, Cohen et al., 2012, Cohen et al., 2001, Whyte et al., 2002, Dingwall and Wilson, 1995). Other work has demonstrated that patients learn from healthcare professionals (Mishel, 1990), and where healthcare professionals have misconceptions relating to medicines, these can be internalised by patients (Angus, 2012). Positioning adherence as a phenomenon of social interaction also supports work that used Social Action Theory (Weber, 1978), whereby action is understood as the behaviour of individuals that has subjective meaning and takes into account the behaviour of others, to understand adherence (Gore-Felton et al., 2005). In the context of the results of this study, adherence actions are presented as social actions due to the constructed social identity embodied by the medicinal product itself, which acts responsively to patients. Social stigma has been highlighted as influencing adherence, supporting the findings of this study (Chai et al., 2014, Anderson et al., 2015). Other evidence that suggests short-term episodes of non-adherence are a function of interaction is also supported (Laba et al., 2015).

Pharmacy-based research in this area has tended to use positivist methods and identified a number of facilitators and barriers to adherence. A well-established conceptualisation of adherence, the Necessity-Concerns Framework (Horne et al., 2013, Stack et al., 2008), is supported by this study, namely in that an essential structure of the experience of adherence in participants in this study was necessity. These findings add to the Necessity-Concerns Framework, suggesting that patients' construction of necessity is based on micro-social and macro-social interactions. Whilst the Necessity-Concerns Framework was described by Donyai (2012) as 'the psychology of the medication' this work may have begun to explore a sociology of medication adherence.

Interpretations of patients' beliefs about the safety and efficacy of a medicine and their pharmacological actions as lay pharmacology are strengthened by the identification in this study of patients' beliefs about the action of medicines (Webster et al., 2009). A study using a sample of ten participants, argues that beliefs and behaviours can be constructed through interactions with medicines (Jones, 2002). Statistical regression has demonstrated that patients with beliefs incongruent with wider societal constructs about 'the chronic disease model' were more likely to experience poor adherence (Mann et al., 2009),

suggesting, as this study has found, that wider societal beliefs construct adherence practices. A meta-synthesis of phenomenological work argues medicines have meaning before they are prescribed for patients, further supporting the findings that patients interact with medicines through wider society, building beliefs about medicines from the social world, throughout their life. (Gamble et al., 2007, Shoemaker and Ramalho de Oliveira, 2008)

This work is also supported by the Common Sense Model (Leventhal et al., 1992a) which describes common sense, i.e. rules of thumb or heuristics, across different classes as part of patients' behaviour in response to symptoms. Two of the classes Leventhal describes relate to 'social comparisons' and 'cultural beliefs and social experiences', highlighting as this study does the importance of social interaction on health behaviours, such as adherence. A further deductive analysis of the data from this study may also find support for other classes of cognitive representations with the Common Sense Model.

This novel perspective can be used to contextualise patients' perceptions of interventions, facilitating future intervention development.

### **What are patients' perspectives of currently available adherence interventions and interventions that are in development?**

Patients' perspectives of interventions varied dynamically. A key finding was the construction of interventions as objects of necessity, which enact interaction between the patient, the product and wider society. A second addition to the literature is the conceptual mapping of patients' perspectives of current interventions onto experiences of adherence, identifying that the majority of interventions represent micro-social interaction and directing future intervention development towards macro-social interactions. This sits in contrast to some normative approaches to adherence intervention development, whereby research has attempted to delineate a 'path to perfect adherence', that describe the experience of adherence as a standard outcome of modifiable and non-modifiable variables. These approaches position adherence as a standard of medicines taking behaviours and, as highlighted by Donyai (2012), enable individuals' behaviours to be predicted, such as in the Health Belief Model or the Integrative Model.

The Integrative Model (Fishbein, 2008) argues that behaviours are more likely to change if they are specific, rather than being concerned with 'improving health' or 'lowering blood pressure', behaviour change interventions are more successful if they are targeted to

specific activities, within specific contexts and times. The findings of this work, whilst suggesting that micro-social interactions are an essential part of the experience of adherence, suggest that interventions should not only target these individual micro-social interactions, but also broader, macro-social interactions. Further work may be needed to ratify elements of this framework, particularly parts pertaining to the 'impact' different interventions might have in relation to behaviour change. For example, the Integrative Model states that interventions based in different domains, considered to be social pressure, attitude and self-efficacy, might have different levels of impact on particular behaviours. Interpreting interventions as macro-social interactions, there is an opportunity for further investigation to explore the domains identified by this study (peers, press, healthcare professionals) and their impact on behaviour change - which may differ at an individual and societal level. Further more, Fishbein's theory has been argued to embody a normative (logical, mathematical) approach to human behaviour and 'does not take account of person-specific variables such as gender, mood and culture' (page 84, Donyai, 2012) which are accounted for in the description proposed by this study.

This work is better aligned to the Fuzzy Trace Theory (Reyna, 2008), which does not adopt a normative approach and identifies experiences of medicines use as subjective, based on patients' own conceptions, beliefs, knowledge and skills. This theory utilises the concept of 'heuristics', describing patients' knowledge as either 'verbatim' or 'gist'. Within this theory is recognition of patients' experiences of remembering the 'gist' of information about medicines. Similarly in this study, participants reported their own 'gist' or 'rules of thumb' about medicines' identities and about adherence that had been generated from social interaction. For example, that participants could miss one or two doses (episodic short-term non-adherence) could be described as a 'gist' in that rather than remembering that medicines must be taken everyday (verbatim) they are reminded that they need to be taken most of the time (gist). This theory is put forward by Reyna (2008) and suggests gist-based intuition develops with age, reducing risky behaviour and that reliance on verbatim memory might reduce the performance of behaviours. It has also been argued that people prefer gist messages rather than verbatim (when given both people remember and act on the gist) (Donyai, 2012). The Fuzzy Trace Theory suggests behaviour change is possible when people interpret facts, knowledge and health information and represent it in their own minds in relation to their own experiences, which is supported by the findings of this study in relation to experiential learning of medicines' identities and medicines taking practices.

## **Do interventions need to be targeted to different disease groups?**

As above, previous work has suggested that interventions to change behaviour are more successful if targeted to specific behaviours within specific contexts. The findings of this study do not dispute this, however, they do raise questions as to the targeting of interventions to groups distinguished by symptomology.

Within normative approaches of understanding adherence, the experience of symptoms, such as pain or breathlessness, that can be relieved by medicines is considered to improve adherence (Cooper et al., 2009). A psychological approach to the adherence phenomenon, the Common Sense Model (Leventhal et al., 1992b) positions somatic disease symptoms as constitutive parts of an internal representation of disease identity. Approaches to coping with symptoms and disease, including when to seek treatment, how to use treatment and when to stop, becomes entwined with representations of disease constructed from previous experiences of illness, interaction with friends and family and healthcare practitioners. Where the findings of this project enhance the Common Sense Model, is the introduction of the notion of medicines' identities that, data from this study would suggest, might represent an additional component of a patient's decision-making processes. Representations that 'drug X relieves symptom Y' could be interpreted as a constructed characteristic of a product, a constituent of that medicine's identity, as considered by the patient at a micro-social level, informed by their interactions at a macro-social level.

The findings of this study diverge from existing models in that rather than conceptualise adherence as the output of an individual's psychological decision-making process, this work describes adherence as an interaction between social actors. Patients are socialised into adherence, constructing medicines taking practices, rather than making decisions, that are pre-predicatively given through interaction with the product and wider society. In essence, whilst this work recognises that symptoms might encourage patients to use medicines, adherence practices are constructed from a broader set of beliefs and values constructed by society that locates symptoms as requiring treatment and medicines as symptom relievers.

This emphasises that whilst society constructs patients' experiences of adherence, these experiences construct society and so societal beliefs about medicines use. In the past, this may have perpetuated social norms concerning adherence, stabilising societies' approach to illness as a 'reaction to symptoms' to fulfil economic agendas, whilst inadvertently encouraging non-adherence in the absence of symptoms as a representation of the

absence of disease. This study highlights a disparity between narratives of medicines use that locate symptoms as a key component of a cost-benefit analysis of the necessity of medicine use and experiences of adherence despite the absence of symptoms of disease. In this study, physical symptoms of illness were one of many representations of disease in both symptomatic and asymptomatic disease groups, with beliefs about medicines use constructed from interaction with wider society enacted through blood tests, referrals from family and friends, prompts from the media, interaction with healthcare professionals and policy changes. This study therefore locates adherence as a response to society, that constructs a response to symptoms.

The medicalisation debate, which refers to a concept whereby healthy or 'symptom-less states' are becoming increasingly categorised as illnesses, is relevant to these findings (Conrad et al., 1987). Some authors go further to distinguish another phenomenon, pharmaceuticalisation, referring to the use of pharmaceuticals without a diagnosis that generates a 'supra-normalcy' only available through pharmacological intervention (Williams et al., 2011, Abraham, 2010). A shift in societal beliefs and practices, away from symptomatic medicines use towards asymptomatic medicines use, has been argued to have been achieved through careful management of clinical trials data and national clinical guideline production (Teira, 2014). Teira argues that during drug discovery, the physicochemical properties of a chemical are identified, and through careful publication of marketing materials and research, such properties becomes linked to the product. Products are then more intensively marketed, prescribed and used as part of treatment or prevention of particular asymptomatic states (such as hyperlipidaemia or hypertension), which constructs and reinforces social conceptualisations of both the product and the asymptomatic state.

Whilst some may argue that this phenomenon represents scientific progress based on evidence, publicity around the changes to medicines use post-licence can be controversial (Gallagher, 2014). Teira labels this phenomenon as collision behaviour, when a risk factor for a disease (such as hyperlipidaemia for cardiovascular events) is transformed into a diagnosis in its own right – which appears to be the case for hyperlipidaemia following a 1984 conference consensus (Tobert, 2014). Similarly hypertension, once noted as a risk factor for a cardiovascular or cerebrovascular event is now diagnosed through blood pressure measurements and represents the treated condition. This move symbolises a shift

in societal beliefs, reconceptualising medicines use as less driven by symptoms and more driven by wider societal constructs about 'when medicines should be taken'.

These phenomena move social practices away from using medicines to treat symptoms, towards adherence to pharmaceutical products without symptoms. These changes, which are argued to be an orchestration of the pharmaceutical industry, appeared to be reflected in the findings of this study, where experiences of symptoms represented a small part in the construction of beliefs about necessity that underpinned the experience of adherence. Indeed there has been documented increases in pharmaceutical use across the globe (Abraham, 2010) with particular criticism of the fierce marketing campaigns, involvement in guideline creation and influence over governmental and charitable organisations, that the pharmaceutical industry employs to promote their products. The interaction between beliefs about medicines and social interaction can be demonstrated through social marketing – between 1995 and 2005, marketing staff for pharmaceutical industry grew by 59%, which led to increased uptake of pharmaceuticals (House of Commons Health Committee, 2005). This reflects back to a late capitalist model of society, outlined earlier in Figure 3, whereby society's conceptualisation of need drive productivity and economic development.

This is relevant to the development of interventions on a societal scale in two ways. Firstly, the construction of necessity (in the presence of symptoms or not) may, to critical observers of the 'adherence agenda', be conceptualised as 'the next wave of medicalisation'. This could be argued to further demonstrate the influence of the bourgeoisie pharmaceutical industry on the beliefs of the proletariat, in the interests of profit. In other words, the construction of adherence as a socially normalised standard of medicines taking practices appears to have generated a necessity for medicines use, identified in this study as part of products' personified identities, that is independent of the experience of physical symptoms, and instead, is based on interactions with wider societal practices. Secondly, further criticism may also be raised around the finding in this study, that locates adherence interventions as objects of necessity, that may represent 'the next wave of pharmaceuticalisation', that seeks to generate a second-line of economic opportunity that posits non-adherence as a socially negative phenomenon and thus interventions (in the form of products or services) as necessary to fulfil socially constructed medicines taking practices. Further work and careful consideration would be needed to explore how this might influence the development of interventions on a societal scale.

## **Limitations of the study**

Whilst the study findings can be described as valid, an integral part of the research process is reflectivity considering the limitations of the study.

A limitation of this study was the sampling method used to identify participants. Community pharmacists and general practitioners were asked to identify participants for the study from their patients, and whilst community pharmacies and general practices were located in areas of low and high deprivation, and successfully resulted in a sample of participants from diverse sociodemographic backgrounds, all of the participants in the study were White British. This may not be surprising given the population profile of North East England. Whilst an advantage of a convenience sampling approach allows for participants to be recruited quickly and easily, a disadvantage of this approach in this study is that the sample recruited was not ethnically diverse. There is potential here then for further investigation of how ethnicity, as the embodiment of culture, language, social practices and social interactions, relates to adherence across different ethnic groups. Though a missed opportunity in this study, further investigation of the experiences of medicines adherence across an ethnically diverse sample may generate insights into how participants living in relation to cis- and trans-ethnic societies (for example, an Indian man living in India versus an Indian man living in England) may experience adherence in relation to socially constructed medicines taking practices, both chronically for settled migrants and acutely for those migrants moving between cultures.

The sampling methods chosen, to identify patients through community pharmacists and general practitioners, may have prevented data being collected by those patients that do not access these services. Indeed these patients may be of particular interest as they could be described as being 'so non-adherent' that not engaging with healthcare structures might prevent access to prescribed medicines. A group that has lower interactions with healthcare professionals and perhaps interactions that differ from typical patterns of social interaction, may represent a set of patients with very different experiences of adherence, and occupy social spaces that do not conform to stereotypical practices of social interaction that might be reflected by the sample. Alternative medicines taking practices may be constructed in these groups, and so further work is necessary that uses a broader sampling approach.

On reflection whilst community pharmacies successfully identified participants for this study, more rigorous monitoring of their activity, such as how many participant packs were not handed out, how many patients said they did not want to be involved, could have been recorded to enable future studies involving patient identification through community pharmacy to be improved. Further details of the general practitioners involved in patient identification should be recorded too to enable future studies to be improved. Additionally feedback and development might be offered to support general practices and particularly community pharmacists as patient identification centres, as part of a research ready agenda that seeks to incorporate collaboration between academia and practice.

Another limitation of this study, also stemming from the convenience sampling method, was the classification of the disease groups. The disease groups that were chosen (cardiovascular disease, diabetes, cancer, gout and chronic obstructive pulmonary disease) aimed to reflect a range of disease states that were asymptomatic and symptomatic. Inadvertently this way of grouping disease states may not have adequately distinguished between physiological diseases and the psychosocial meanings attached to diagnosis. For example, when identifying participants with cancer, a range of participants were recruited with different types of cancer (including breast, colon, prostate and lung) which when considered on reflection, represent very different physiological diseases, but perhaps represent something quite similar to lay people who might understand cancer to be one disease. Due to the broadness of the disease categories not all participants reflected the intended symptom profile. Whilst participants did not necessarily reflect the intended symptomology, this highlights that what is 'known' about the physiology of disease by adherence researchers, may not always be reflected in the reality of the lived experience of the disease. This emphasises the importance of the presuppositions of researchers in relation to study design. In some way such a varied sample can be interpreted as a strength of study, as participants were drawn from a range of diagnostic, physiological, symptomatic and lay perspectives that could be argued to add depth to the data.

A final limitation of the study could be that the study reflects the experience of illness rather than adherence. Ingadottir (2009) explains that a limitation of her phenomenology is that rather than the experience of adherence, it reflected the experience of having diabetes. Ingadottir accepts the limitations of her work and suggests a way around this would be to investigate multiple conditions within a phenomenology of adherence, as has been done in this study. Despite the inclusion of participants from multiple disease groups,

it could be argued that this study represents participants' experiences of long-term illness, of which medicines use makes up, whilst important, only one part. To argue that this work is a phenomenology of the experience of chronic illness however, would negate other important aspects of that experience that were not included as part of this study, such as changes to diet and exercise or the use of medical devices, for example.

The project adds to the adherence literature by presenting a novel description of patients' experiences of adherence. Rather than being directed towards micro-social experiences of necessity constructed by an individual patient's experience of medicines use, conceptually mapping patients' perspective of adherence interventions has identified potential avenues of future intervention development that are opened up to experiences constructed through macro-social interaction, i.e. the social experience of medicines use. The implications of these findings raise questions as to the driving forces of the 'interventionalisation' of the adherence agenda, as a representation of evidence-based progress or bourgeois economic development. For some this may raise moral, ethical and legal questions whilst for others it represents evidence-based progress and economic opportunity. As such careful consideration of future work is needed to develop interventions that utilise macro-social interactions that positions commercial opportunities sympathetically to moral and ethical matters.

### **Implications of this research**

Interpreting the results of this study with relevant literature has generated novel insights into patients' lived experiences of adherence across a range of disease states and identified patients' perspectives of adherence interventions. The insights developed from this study can be used to argue that the future direction of intervention development need not focus on symptom-specific interventions and might further explore the domains of social interaction. This is discussed in more detail below.

#### ***Locating adherence interventions within social domains***

Whilst empirical work is needed to support these interpretations, thus far adherence interventions appear to be most commonly located within the micro-social interaction between the patient and the product. These interventions, such as electronic packaging, reminder alarms, and multi-compartment compliance aids, become part of the product identity and can be recognised as embodiments of unique relationships between a patient and a product. These interventions then go straight to the heart of the personification of

medicines, recognised and defined here as the abstract and conceptual identities that medicines take on in society, becoming the embodiment qualities and characteristic that improve, enable, and maintain survival. This focus positions medicines, not only as independent, conceptual social actors within a patient-product relationship, but also within a broader pre-supposed social context. Educational interventions, behavioural interventions and other complex behaviour change interventions all reflect an interaction between a patient and the beliefs of healthcare professionals, and go some way in attempting to construct patients' beliefs, ideals, and values towards adherence. That is to say, that these interventions attempt to construct predicative approaches to medicines taking, such that patients' values are changed and micro-social interactions between the patient and the product modified. What has yet to be explored as a direction of intervention development, is the construction of beliefs and values through social interaction with peers and press. Although already developed as educational and behavioural interventions, further exploration into interactions with health professionals might explore the consistency of interactions between healthcare professional groups, such as those with doctors, nurses and pharmacists, to ensure a consistent 'message' or 'gist' is being constructed during interactions.

***Interventions that use family and friends to improve adherence***

Engaging with family members, friends, and peer patients, to influence the adherence of a patient presents itself as a contrast to patient-centred or patient-focused care. Encouraging family members, friends and peer patients to 'buy in to' treatment plans and prescriptions may not represent a novel approach to improving adherence, in practice, engaging formal carers, who may be family members or friends, with prescribing decisions is well-established. However a novel direction for intervention development may be to include broader family members, friends and peer patients, as part of the adherence intervention. Encouraging these actors to take on a role with an adherence intervention may cause concern for some patients, healthcare professionals and policy makers. An already developed intervention that could be interpreted as a macro-social interaction with friends and family might be peer-support groups or formal discussion groups that are currently used as part of rehabilitation plans. In focus groups these interventions were not viewed positively, rather participants appeared to have these interactions more informally, whilst doing other activities that contributed to their social life. There may be an opportunity here then for adherence interventions to target social activities, such as football matches, bingo halls and other social events. These interventions would be supported by Chartrand and

Bargh's (1999) work on social interaction and the perception-behaviour link. Their work argues that just by seeing or interacting with people doing a particular task, people are more likely to match that behaviour, consequently such interventions may include the encouragement of self-administration of medicines in a social setting – this might be compared to other social changes such as smoking in enclosed spaces and wearing seatbelts. A concern here however is that non-adherent patients interacting with patients who are adherent might result in adherent patients becoming less adherent, thus any investigation would need to consider and mitigate the ethical implications of such an intervention. Further work might explore how informal interactions between patients, peers, family and friends can be optimised to improve adherence.

### ***Interventions that use the media to improve adherence***

Turning to another domain of macro-social interaction, the media, may present a novel approach to intervention development. In this context, press could be interpreted as all aspects of 'social knowledge' including that printed in newspapers and magazines but also heard on the radio, seen on the televisions and found on the Internet. At present, this domain of interaction is largely underdeveloped in relation to adherence interventions. The majority of interactions with the press present medicines taking as a construct of negative necessity (i.e. medicines should only be used to treat illness when needed). Here interventions may be enacted through regular television advertisements, appropriately timed television or radio announcements, Internet-based pop-ups or even more simple strategies, that use pro-medicines material to posit medicines use as routine, rather than based on need as per current marketing agendas.

Consideration should be given to how direct-to-consumer pharmaceutical advertising of medicines, such as in the United States of America and New Zealand, might influence patients' adherence practices. The advantages of advertising are well identified; briefly including increasing patient empowerment through education, promoting dialogue between patients and healthcare providers, reducing under-diagnosis and under-treatment and improving adherence (Ventola, 2011). One way to reconsider advertising maybe to move the marketing message away from initiation of medicines and towards continuation of medicines and good medicines taking techniques. Concerns in the UK around direct-to-consumers advertising centre on the overemphasis on the benefits of medicines use that misinform patients about the risks associated with medicines that may lead to inappropriate prescribing. Ventola also reports that increased advertising 'manufactures

disease', highlighting the impact interaction with the media has on patients' construction of necessity beliefs. Whilst the place of direct-to-consumer pharmaceutical advertising remains negotiable, its impact on the construction of medicines taking practices on a social scale must be carefully considered moving forward.

This interpretation supports the development of interventions based on social media. Whilst these interventions might serve as reminders to patients initially, over time they are likely to become integral to the patient-product relationship, as creators of social knowledge that constructs medicines taking as normal, positive or neutral (as oppose to a negative necessity). This domain of interventions may go some way in constructing pre-predicative beliefs about adherence to medicines prior to the development of a patient-product relationship (i.e. before the patient is prescribed anything), constructing patients' knowledge about adherence and medicines taking as a phenomenon of everyday life.

Interventions based on macro-social interaction through the television or radio may present ethical and legal dilemmas, in relation to how patients are encouraged to use their medicines, and consequently such interventions would need to be considered cautiously and supported with further evidence collected from patients, professionals and policy makers, to circumvent the inappropriate use of medicines. The use of television and radio media to promote medicines use may feed into concerns and debate on the pharmaceuticalisation of society, particularly in relation to funding arrangements, be it from the NHS, the government or the pharmaceutical industry. These tensions too must be carefully considered and supported with further work to prevent barriers to intervention development and implementation.

#### ***Interventions that use policy to improve adherence***

Further reflection on wider social influences on adherence highlights policy as an arena of future intervention development. This may include changes to how medicines are conceptualised socially through policy, licensing and authorisation processes. In the domain of policy, medicines appear to be conceptualised as dangerous unless proven beneficial. This positions adherence as an embodiment of necessity, where medicines should only be prescribed, and taken, when needed as a negotiation of risk-benefit. This can be demonstrated when considering the policy on direct-to-consumer pharmaceutical advertising; the US Food and Drug Authority's policy on advertising stipulates that advertisements that include product claims must also include risks. This has developed more recently so that rather than including every risk associated with a product's use, only

the major risks need be included, with a caveat that patients are directed to sources of further information (Ventola, 2011). A novel direction for adherence interventions then, might be to reconstruct the way medicines, as medico-legal objects, are governed, thereby reconceptualising medicines, and so adherence, as something other than a phenomenon of necessity. As participants did not refer to interventions that changed policy approaches during discussions on interventions directly, further work would be needed to establish if interventions that seek to change policy might lead to a change in the construction of beliefs about medicines as objects of necessity.

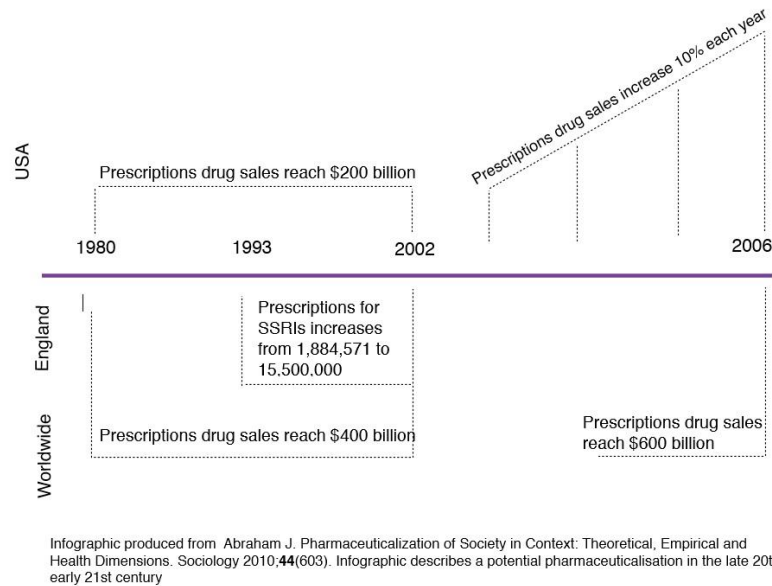
The UK's National Institute of Health and Care Excellence's (NICE) guideline on medicines adherence (National Institute for Health and Clinical Excellence, 2009) advocates that interventions are tailored to meet patients' individual needs, with an emphasis on patients being given an appropriate amount of information to make an informed decision. The guideline does not recognise medicines adherence as a social phenomenon, where information to make an informed decision is often generated through social interaction with lay sources of knowledge. Policy makers must consider the wider social determinants of adherence, such as exposure to information in newspaper headlines, on the Internet and generated through interaction with family and friends and consider using public health campaigns to help patients identify and 'get to know' their medicine as tacit identities. Additionally health professionals could highlight the need to scrutinise information about medicines that patients may be exposed to from social interaction, encouraging patients to discern between robust, scientifically informed medicines information and lay knowledge.

Interventions that would seek to use media to promote adherence directing intervention development towards changing policy in relation to medicines sale, supply and advertising would require careful consideration and management of ethical and legal tensions, particularly in relation to popular debates concerning medicalisation and pharmaceuticalisation of society.

***Society and Pharmaceuticals: ethical implications of using social domains as adherence interventions***

Implications of this research have been considered in relation to intervention development. What has become clear during the course of this project is the ethical dilemmas presented when conducting adherence research, both on an individual researcher level (Rathbone and Jamie, 2016) but also on a broader level in relation to 'interventionalisation' of the

adherence phenomenon. A report by Abraham (2010) outlined the significant rises in the global use of pharmaceuticals (see Figure 12) and directed attention towards the behaviour of the pharmaceutical industry in relation to social marketing of pharmaceutical products.



**Figure 11. Pharmaceuticalisation of society (data from Abraham 2010)**

Whilst definitions of the phenomena vary, social media commentators of pharmaceuticalisation has become somewhat quasi-conspiratorial, with some extending the debate to public health (Camargo Jr., 2013, Figert and Bell, 2014). Ethical issues are raised where a macro-social intervention might try to change patients' beliefs, values and behaviours to increase adherence, and so medicines use, for commercial purposes. Consumer scrutiny of the pharmaceutical industry, healthcare providers and healthcare professionals is generating concern over increasing medicines use, with deprescribing becoming a topic of research interest (Thompson and Farrell, 2013), which might increase following the development of a societal level intervention. Whilst the commercialisation of the adherence phenomenon may present itself as a difficulty for some, a view can be taken that in akin to pharmaceutical development, that without commercialisation, future funding for further research and scientific advancement may not be available. Despite this, the commercial incentive of 'interventionalisation' may raise issues for some, particularly when this leads to changes in societal values concerning medicines use.

Indeed macro-social intervention may go further and wrest back patient choice from patients to professionals, returning the adherence narrative to the more paternalistic, 'compliance' agenda of previous decades. As the 'concordance agenda' empowered

patients to make agreements with their prescribers about medicine use, and the 'adherence agenda' arguably encouraged patient choice, 'interventionalisation' of the phenomenon, enacted through a macro-social interventions, may disempower patients at an individual level.

There are clearly different interpretations of the ethical location of 'interventionalisation', consequently further work is needed to explore patients' and professionals' views of this phenomenon as well as consider the broader historical and sociological perspectives.

## **Conclusion**

This work describes patients' lived experiences of medicines adherence as constructed through micro- and macro-social interaction, describing the experience as a response to society, not merely a response to symptoms.

The synthesis of findings from interviews and focus groups present a novel description of adherence, as a phenomenon of social interaction. The experience of adherence as a social phenomenon locating medicines use as a life-long experience whereby patients are continuously interacting with medicines, as personified products, or with wider society; constructing beliefs, values and medicines taking practices that structure experiences of adherence. Adherence interventions were identified as modes of interactions, forming part of the personified medicines identity or embodiments of macro-social interaction with wider society.

Interpretation of this work has identified new avenues of intervention development in macro-social domains, directing future work towards large-scale social interventions rather than patient specific products. Further work is needed to establish the impact of interventions within these domains and identify key interactions that might be exploited to improve adherence. Care must be taken in relation to the development of interventions within a macro-social context, with particular sensitivity to debates concerning the medicalisation and pharmaceuticalisation of society. Debates concerning direct-to-consumer pharmaceutical advertising might be re-engaged to initiate further discussion on types of advertising that might be used to promote adherence to medicines that are already prescribed, moving away from advertisement to promote initiation of medicines and towards advertisement of continuation.

Patient interactions with healthcare professionals, whilst enacting established societal approaches to medicines use, such as evidence-based medicine, might construct conflicting

medicines taking practices in patients through divisions of expertise and differences of professional opinion and practices. Preliminary work has identified that improvements in adherence may be achieved where healthcare professionals share perspectives as to how medicines should be used (Rathbone et al., 2016). This suggests that additional exploration may be needed to identify the influence of inconsistencies between interactions with professionals (or other groups such as family and friends) has on medicines use.

That medicines use exists as a response to society, how patients interact with medicines that have moved or are moving between societies represent another area of interest that will add depth to these findings. Medicines taking practices constructed in different social settings, such as a small town in India, may translate into difficulties with assimilation or the reconstruction of medicines taking practices were patients have emigrated to a small town in the UK. Additional conflict may also be experienced where patients move between cultures or social norms as they move through the domains of interaction outlined above. For example, using American products, reading and watching Indian media and mixing with family and friends from diverse ethnic backgrounds within a British policy context. This framing of medicines use offers new opportunities of investigation of the adherence phenomenon from sociological perspectives.

## Appendix A: Supplementary material

**Table 4. Summary of studies that conceptualise adherence**

Author	Thematic or Conceptual Framework	Outcome of the Study
Garavalia, L., et al., Exploring patients' reasons for discontinuance of heart medications. <i>J Cardiovasc Nurs</i> , 2009. 24(5): p. 371-9.	The Health Belief Model	The most common reason for non-adherence was adverse effects that impaired daily life
Garay-Sevilla, M.E., J.S. Porras, and J.M. Malacara, Coping strategies and adherence to treatment in patients with type 2 diabetes mellitus. <i>Rev Invest Clin</i> , 2011. 63(2): p. 155-61.	Jalowiec Coping Scale (Cognitive, Avoidant, Fatalistic, Supportant)	Facilitating psychosocial factors, such as coping, must be carefully considered to foster optimal adherence
Gault, I., A. Gallagher, and M. Chambers, Perspectives on medicine adherence in service users and carers with experience of legally sanctioned detention and medication: a qualitative study. <i>Patient Prefer Adherence</i> , 2013. 7: p. 787-99.	Treatment Satisfaction	Professionals and the relationship between the professional and the patient is essential for optimum adherence
Girdwood, C.P., Predicting adherence in a multifaceted medical regimen. 2008, ProQuest Information & Learning: US.	The Self-efficacy Adapted Health Belief Model	Adapting the Health Belief Model to include self-efficacy did not improve the models capacity to predict adherence
Gore-Felton, C., et al., The Healthy Living Project: an individually tailored, multidimensional intervention for HIV-infected persons. <i>AIDS Educ Prev</i> , 2005. 17(1 Suppl A): p. 21-39.	Social Action Theory	Tailored-intervention designed and are currently being evaluated
Hampson, S.E., R.E. Glasgow, and D.J. Toobert, Personal	Personal Models	Composites of patients' Personal Models were cause, symptoms,

models of diabetes and their relations to self-care activities. Health Psychology, 1990. 9(5): p. 632-646.		treatment and seriousness and determine self-care behaviours
Lai, W.A., W.C. Chie, and C.Y. Lew-Ting, How diabetic patients' ideas of illness course affect non-adherent behaviour: A qualitative study. British Journal of General Practice, 2007. 57(537): p. 296-302.	Kleinman's Explanatory Model	Side-effects were seen as a consequence of taking medication, which resulted in increased dosing to combat side-effects.
Marshall, I.J., C.D. Wolfe, and C. McKevitt, Lay perspectives on hypertension and drug adherence: systematic review of qualitative research. BMJ (Clinical research ed.), 2012. 345: p. e3953.	Geo-Ethnic and Cultural	Beliefs about adherence are remarkably similar across ethnic, cultural and geographic groups.
Mohamed Ibrahim, O.H., F.J. Jirjees, and H.J. Mahdi, Barriers affecting compliance of patients with chronic diseases: A preliminary study in United Arab Emirates (UAE) population. Asian Journal of Pharmaceutical and Clinical Research, 2011. 4(SUPPL. 2): p. 42-45.	Chronic Disease	Level of education and chronic diseases are not correlated with adherence
Nurymberg, K., S. Kreitler, and K. Weissler, The cognitive orientation of compliance in short- and long-term type 2 diabetic patients. Patient Education and Counseling, 1996. 29(1): p. 25-39.	The Theory of Cognitive Orientation	Long-term adherence can be predicted through assessing patients goals, values and self-image.
Parveen, M. and S. Piyaali, Treatment compliance to diabetes care: A cross-sectional study from Pakistan. Value in Health, 2011. 14 (3): p. A98-A99.	Education	Non-adherence should be identified and patients should be educated accordingly.
Zarani, F., et al., Effectiveness of the information-motivation-behavioral skills model in the adherence rate of coronary artery bypass grafting patients. Psychological Research, 2010. 12(3-4): p. 24-43.	Information-Motivation-Behavioural Skills Model (IMB)	A theory-driven psycho-educational intervention improved adherence.

**Table 5. Summary of studies that use different methods of measuring adherence**

<b>Reference</b>	<b>Name of Method</b>	<b>How is it done or calculated?</b>	<b>Reported Conclusion</b>
An, J.J. and M.B. Nichol, Impact of multiple medication compliance on cardiovascular outcomes in patients with type ii diabetes and comorbid hypertension controlling for endogeneity bias. Value in Health, 2011. 14 (3): p. A8-A9.	Proportion of Days Covered	Total days all medicines available/ days in interval = PDC range 0-1(Barner, 2010)	0.63 Diabetes 0.69 Hypertension 0.53 Comorbid
Barnestein-Fonseca, P., et al., Is it possible to diagnose the therapeutic adherence of patients with COPD in clinical practice? A cohort study. BMC Pulm Med, 2011. 11: p. 6.	Self-reported Adherence (includes Haynes and Sackett Method, Morinsky Green Test and Bataala Test)	The participant estimates how often they are non-adherent or answers questions about their disease	100% (Hayes-Sacke test ), 60.8% (Morisky-Green Test) and 46.9% (Batalla Test) respectively  *Threshold 80-110%
Barnestein-Fonseca, P., et al., Is it possible to diagnose the therapeutic adherence of patients with COPD in clinical practice? A cohort study. BMC Pulm Med, 2011. 11: p. 6.	Dose Count	Counts the number of doses administered over a specified time interval. Can be monitored electronically	68.1% Adherence
Carney, R.M., et al., Adherence to a prophylactic medication regimen in patients with symptomatic versus asymptomatic ischemic heart disease. Behavioral Medicine, 1998. 24(1): p. 35-39.	Electronic Packaging	Product packaged in unobtrusive electronic adherence measure	62.4% Symptomatic heart disease 77.4% Asymptomatic heart disease
Edwards, D.L., Psychological factors affecting adherence and metabolic control in diabetes mellitus. 1999, ProQuest Information & Learning: US.	Self-reported Adherence (Questionnaire)	Hierarchical regression analysis	Results of the study associate conscientiousness with better self-reported adherence, mediated by coping and self-efficacy

Farmer, A., A.L. Kinmonth, and S. Sutton, Measuring beliefs about taking hypoglycaemic medication among people with Type 2 diabetes. <i>Diabetic Medicine</i> , 2006. 23(3): p. 265-270.	Self-reported Adherence (Medication Adherence Report Scale - measuring belief and intention)	Ordinal Questionnaire	Median Score 25
Foley, K., G. Carls, and P. Roberto, Medication adherence and medical cost offsets: A review of the literature. <i>Value in Health</i> , 2012. 15 (4): p. A20	Medication Possession Ration	Number of days of medication supplied / number of days between supplies (Barner, 2010)	> 80% adherence threshold
Gialamas, A., et al., Does point-of-care testing lead to the same or better adherence to medication? A randomised controlled trial: the PoCT in General Practice Trial. <i>Med J Aust</i> , 2009. 191(9): p. 487-91.	Self-reported Adherence (Five-Item Medication Adherence Report Scale – MARS5)	Abbreviated Ordinal Questionnaire	39.3% Intervention 37.0% Control
Haynes, R.B., et al., Interventions for enhancing medication adherence. <i>Cochrane Database Syst Rev</i> , 2008(2): p. CD000011	Medication Event Monitoring System MEMS (as well as others)	Added to packaging to record each time packaging is accessed	> 80% adherence threshold
Jain, S. and S. Jadhav, Pills that swallow policy: clinical ethnography of a Community Mental Health Program in northern India. <i>Transcult Psychiatry</i> , 2009. 46(1): p. 60-85.	Ethnography	Discussion and observation from within a culture-sharing group	Medication has several symbolic meanings which differ between policy makers and patients
Kohlmann, C.-W., et al., Associations between type of treatment and illness-specific locus of control in Type 1 diabetes patients. <i>Psychology &amp; Health</i> , 1993. 8(5): p. 383-391.	Adherence as an outcome of Locus of Control	Ordinal psychological scales	Associated locus of control and knowledge of disease with adherence

Li, D.S., Patient centered care approach to adherence with cardiovascular medications: Self-determination theory integration. 2010, ProQuest Information & Learning: US.	Survey	Series of questions assessing adherence on a scale of 1 to 5	Self-determination theory patient-centered care may improve adherence.
Lou, Y., et al., The implications of evaluating medication adherence at different drug classification levels. Value in Health, 2013. 16 (3): p. A13.	Proportion of Days Covered (three methods)	Method 1: based on drug class and weighted averages Method 2 and 3: based on drug indication (anti-diabetic) and Medicare Generic Drug Identifiers (GPI6 and GPI 10 respectively)	0.64 Method 1 0.69 Method 2 0.69 Method 3
Toussi, M., et al., A novel method for measuring patients' adherence to insulin dosing guidelines: introducing indicators of adherence. BMC Med Inform Decis Mak, 2008. 8: p. 55.	Electronic Database	Patient registers each dose on a database, creating a record of dose and time	45% Absolute Agreement 30% Relative Agreement 2% Extreme Disagreement 26% Under-treatment 30% Over-treatment
Van der Elst, E.M., et al., High acceptability of HIV pre-exposure prophylaxis but challenges in adherence and use: qualitative insights from a phase I trial of intermittent and daily PrEP in at-risk populations in Kenya. AIDS Behav, 2013. 17(6): p. 2162-72.	Qualitative Interviews	In-depth interviews of participants in a trial	Side effects were acceptable, social stigma, and complexities of daily life influence adherence
Vervloet, M., et al., SMS reminders improve adherence to oral medication in type 2 diabetes patients who are real time electronically monitored. Int J Med Inform, 2012. 81(9): p. 594-604.	Real Time Medication Monitoring	Dose is registered on a system within a pre-defined time interval	50% with SMS reminder 39% without reminder
Weinstein, C., et al., Patient versus clinician assessment of compliance with study medication in a study	Self-reported Adherence and Clinician	Discussion by patients and clinician	Over-estimates compliance by 20%

with fixed-dose mometasone furoate/formoterol combination. American Journal of Respiratory and Critical Care Medicine, 2011. 183 (1 Meeting Abstracts).	Reported Adherence	respectively	
Weinstein, C., et al., Patient versus clinician assessment of compliance with study medication in a study with fixed-dose mometasone furoate/formoterol combination. American Journal of Respiratory and Critical Care Medicine, 2011. 183 (1 Meeting Abstracts).	E-Diary	Patients record if they took the dose or not in an electronic diary	71% Adherence
Weinstein, C., et al., Patient versus clinician assessment of compliance with study medication in a study with fixed-dose mometasone furoate/formoterol combination. American Journal of Respiratory and Critical Care Medicine, 2011. 183 (1 Meeting Abstracts).	Integrated Dose Counter	Represents the number of remaining doses in the inhaler	72% Adherence
Williams, G.C., et al., Reducing the health risks of diabetes: how self-determination theory may help improve medication adherence and quality of life. Diabetes Educ, 2009. 35(3): p. 484-92.	Self-reported Adherence	Postal Survey assessing self-regulation of medicines use	Adherence linked to psychological measures of self-determination theory
Wu, J.R., et al., Factors influencing medication adherence in patients with heart failure. Heart Lung, 2008. 37(1): p. 8-16, 16.e1.	Interview Content analysis	In-depth interviews transcribed and analysed	Desire to be healthy was the primary motivator in a decision to adhere to medication
Yamada, H. and M. Nakashima, A new electronic event monitoring device for recording of medication compliance. [Japanese]. Japanese Journal of Clinical Pharmacology and Therapeutics, 2001. 32(5): p. 249-253.	Electronic Monitoring Device	Novel device contains medication, opening device releases medication and records time and date	100% Adherence – no pills were left in the device

**Table 6. Summary of Medicines Adherence Intervention Review Articles**

<b>Studies</b>	<b>Disease</b>	<b>Intervention</b>	<b>Outcome</b>
Al-aeel et al., 2011	Epilepsy	1. education and counselling 2. behavioural - reminders	Inconclusive review
Al-Qazaz et al., 2011	Diabetes	1. education	Inconclusive
Armout et al., 2008	Asthma, Diabetes, Cardiovascular Disease,	3. pharmacy-based	Inconclusive review
Bain-Brickley et al., 2011	HIV	4. nurse-led home-based intervention 5. peer-support group therapy 6. patient medication diaries	Inconclusive review
Bangalore et al., 2004	Tuberculosis Hypertension HIV Diabetes	7. regimen simplification - combination regimens	Slight improvement [poor definitions of adherence]
Cutrona et al., 2010	Cardiovascular Disease	8. person-independent [automatic messages delivery via electronic or traditional means] 9. person-dependant [phone calls, in-person interventions]	56% of interventions were successful (67% of the successful interventions were electronic). In-person in-pharmacy interventions were the most successful. Further research needed.
Dolder et al., 2003	Schizophrenia	1. education 2. behavioural	The greatest improvement seen with longer interventions made up of a combination of educational, behavioural and affective strategies.

Haynes et al., 2008 [Cochrane Review]	Multiple	1.education 2. behavioural - reminders 5. peer-support group therapy 10. more convenient care 11.self-monitoring 12.crisis intervention 13.telehealth	Inconclusive review
Higgins et al., 2004	Multiple diseases in patients > 65-years old	1. education 14.external cognitive support	Inconclusive review
Lindenmeyer et al., 2006 [Cochrane Review]	Diabetes	education 2. behavioural - reminders 15. packaging	Although evidence was of limited quality due to problems measuring adherence, pharmacist-led interventions improved medicines adherence in diabetes.
Linn, A et al., 2011	Multiple chronic medications	16. Internet-based interventions	Further evidence is needed but there is a small amount of good evidence supporting the use of internet-based interventions to improve adherence. Internet-based interventions involve online assessment, tailored content delivery and feedback in the form of customised health programs.
Lutge et al., 2012	Tuberculosis	17.material incentives (including cash)	Inconclusive due to poor generalizability and overall quality of the evidence, although higher cash incentives showed slightly more promise than low cash, or other material, incentives.
M'Imunya et al., 2012	Tuberculosis	1.education 2. behavioural - counselling	Some evidence to support education and counselling techniques however magnitude of improvement varies between contexts. More research on matching the nature of the intervention to the reasons for non-adherence
Mahati et al., 2011 [Cochrane Review]	Multiple	2. behavioural - reminders	Update to a Cochrane review concluded that there was evidence to justify the use of 'reminder packaging' but further research is needed to determine their usefulness in different diseases, age, differences between packaging styles and impact on clinical outcomes.

Newell et al. 1999	Cardiovascular Disease	1. education 2. behavioural - reminders and counselling 7. regimen simplification - dose frequency 17.telehealth 18. supplying medication as confectionary 19.Complex Intervention 15. packaging	No evidence to support physician-focused interventions, only complex interventions or reducing dose frequency showed any success but methodologies were not robust so no strong recommendations can be made.
Odegard et al., 2007	Diabetes	3. pharmacy-based interventions 2. behavioural interventions and reminders 15. packaging 17. telehealth 19. Complex Intervention	Inconclusive evidence to support interventions, although one study supported the use of a combination of interventions (made up of reminders and packaging)
Ruppar et al., 2008	Older people	1. education 2. behavioural - skills	Gaps in the literature included reminders, self-monitoring strategies, carer-strategies (as oppose to self-medicating). Further evidence is required
Ryan et al., 2011	asthma glaucoma cardiovascular disease depression and schizophrenia malaria HIV/AIDs respiratory infections and Tuberculosis Diabetes contraceptive	1. education 2. behavioural - skills, change, reminders, counselling, 3. pharmacy-based services 7. regimen simplification 11.self-monitoring 15. packaging 19. complex intervention	No evidence for people with co-morbidities.

Schedlbauer et al., 2010 [Cochrane Review]	cardiovascular disease (lipid lowering medication)	1. education 2. behavioural - reminders 7. regimen simplification	Reminders showed the most significance although overall evidence was low.
Schroeder et al., 2004	Hypertension	1. education 2. behavioural - motivational counselling 7. regimen simplification 19. complex interventions	Heterogeneity of studies prevents firm conclusions, complex interventions showed greatest improvements in adherence, education alone was unsuccessful, motivational interventions were promising but regimen simplification should be deployed as the first-line until further evidence is available
Touchette et al., 2008	Multiple chronic medications	1. education (informational) 2. behavioural 19. complex interventions	Combinations of interventions and simplification of medicines showed promise however the evidence base did not support any one intervention outright. Future research to focus on matching or tailoring interventions to patients.
Van Dam et al., 2005	Diabetes	5. peer-support 13. telehealth (including internet)	This systematic review concluded tentatively that social support must come from appropriate sources (peer-patients or healthcare professionals rather than spouse or family). Further research is needed with better methodological designs.
Vervloet et al. 2012	HIV Glaucoma Cardiovascular disease Asthma Contraceptives	2. behavioural - reminders (SMS text messages/pager system)	The long-term efficacy of reminder interventions was unclear although some short-term improvements were made in adherence up to 6 months. The content and timing (weekly or daily) requires further research.
Waterman et al. 2013 [Cochrane Review]	Glaucoma	1. education 2. behavioural - daily-living and reminders 7. regiment simplification 11. monitoring	Inconclusive, further evidence needed

Williams et al. 2014	Diabetes (type 2)	1. education 2. behavioural – daily reminders 3. pharmacy- based services 5. peer-support 13. tele-health (including internet)	Heterogeneity of studies makes conclusions tentative.
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**Table 7. Summary of Included Studies in Systematic Review**

Author	Country	Context	Methods	Sample Size	Sample	Type of phenomenology	Description of medicines adherence	Summary
Abedian et al. (2010)	UK	Sickle Cell Disease	In-depth semi-structured interviews	10	6 women, 4 men, with HbSS genotype sickle cell anaemia, self-identified Afro-Caribbean, 18-52 years	Interpretive	The study did not explicitly report a description of the experience of medicines adherence	Patients understood the importance of using penicillin and were happy they had received enough information from their doctor/nurse. Adherence was influenced by polypharmacy, duration, schedule, dosage, 'lack of immediate consequences', lifestyle and physical and psychological adverse effects. The study concludes that simply educating patients about their medicines will not influence adherence; that patients' concerns, beliefs and personal attitudes need to be elicited and redressed if adherence is to be improved.
De Geest et al. (1994)	Belgium	with 'lifelong medication dependency' (patients with epilepsy, cardiac and renal transplant)	Interviews	14	7 women and 7 men	Descriptive	Adherence was described environmentally as a kin to eating and drinking, personally as negotiated by emotion and relationships	Identified themes of i) personal attributes, including emotional distress, confidence in the physician, normalcy and perceived health status, ii) environmental attributes, including routine, distraction, social support and cost, and finally iii) self-efficacy, negotiated by adverse effects, formulation, medication aids and dosing schedule. The work attempts to map these findings within the context of Bandura's Self-Efficacy framework to produce a tool to monitor medication taking

							with others and through self-efficacy, which was mediated by interactions with the drug and the regimen.	behaviour.
De Moss et al. (2014)	America	HIV	In-depth semi-structured interviews	12	Middle-aged, black women, aware of their HIV status for at least 2 years from the 'deep south' (Atlanta, Georgia, USA)	Not reported	Significant events lead to changes in perspective and motivation to adhere to HAART, recognition of 'personal strength' to adhere to regime facilitated adherence and this was mediated by trust in the healthcare provider.	This qualitative study of 12 middle-aged black women presents a novel understanding of adherence to HAART. The authors used in-depth interviews to explore themes related to adherence. The authors identified three main themes, i) significant life event ii) recognition of ability to adhere/be healthy iii) relationship with health services. This work speaks to the 'healthy adherer' concept whereby once women recognise their self-efficacy are able to adhere 'more strongly'. Paradoxically this research also showed that negative experiences of health services promoted adherence to HAART as women avoided hospitalisation/further interaction with health services.

Enriquez, Lackey, O'Connor and McKinsey (2003)	America	HIV	60-120 minute in-depth interviews using a series of open-ended questions	13	Adherent for one year following non-adherence who became adherent without formal intervention, 11 men and two women	Husserlian	The findings from this study included i) cycle of non-adherence and negative health behaviours following diagnosis, ii) a significant life-event leading to a decision to be adherent and iii) readiness for adherence where patients adhered to treatment.	This phenomenological investigation into the experiences of medication adherence to HIV treatment following a period of non-adherence elicited a detailed description of the phenomenon of readiness for adherence. Readiness followed a significant life event which triggered a desire for <i>life</i> and other healthy behaviours. The study was in 13 HIV positive individuals (11 men and 2 women) recruited through secondary care. Their HIV adherence was measured according to a clinical marker.
Gamble et al. (2007)	UK	Asthma/corticosteroids	Interviews	10	3 males, 7 females, with 'difficult asthma', aged 25-48	Hermeneutic Interpretive	Adherence is made up of a complex set of decisions that are iterative and dynamic, mediated by continual change	The study identified five themes, i) fear of adverse effects ii) knowledge is power iii) weighing up costs and benefits iv) loss of self v) impact on lifestyle

Hansen, Holstein and Hansen(2009)	Denmark	General	35-106 minute interviews	20	20 young women who have experienced taking medicines	Schutz' phenomenology (life-world)	Young women had negative attitudes towards taking medicines but this perspective was overcome by the demands of everyday life and the indication of the medicine.	The study found that women generally have a negative attitude towards medicines taking but found that other goals took priority over their negative attitude. The goal, or indication of the medicine over-powered their desire not to take medicines.
Henriksen and Parnas (2013)	Denmark	Schizophrenia	Not reported	Not reported	Not reported	Not reported	The patient does not experience their initial self-disorder from which psychosis emerges as 'symptoms' of an illness and consequently their existence and identity are not compromised internally, leading to non-	This phenomenological inquiry into insight in schizophrenia and it's relation to poor compliance provides a novel, detailed perspective of compliance. Although the paper does not state methods, data collection, analysis or empirical results, the paper delivers robust phenomenological insights.

						adherence
Jones (2002)	US	HIV/AIDS	Semi-structured interviews	9	3 women, 6 men, with HIV infection from occupational exposure, sexual transmission and contaminated blood products, over 18 years old, could speak English who had taken medication for longer than 6 months, 8 Caucasian and 1 Hispanic	<p>Not reported</p> <p>Adherence to antiretroviral therapy by nurses with HIV was described as a double-edged sword. Describing adherence as 'life-changing'</p> <p>The study used qualitative interviews to understand the experience of adherence to anti-retroviral medication by nurses with HIV in the United States of America. The study describes adherence as a life-changing phenomenon and identified six themes, i) managing and being managed by the meds ii) coping with the meds iii) feeling lousy iv) negotiating the hassles and the cost v) living under a dark cloud and an encompassing theme of vi) becoming a patient. The authors highlight 'symbiosis', 'normalisation' and an appreciation of the 'life-long' nature of adherence. The work concludes by identifying participants as 'wounded healers' and advocates support groups.</p>
Jones (2003)	US	HIV/AIDS	Semi-structured interviews	10	HIV positive, over 18 years old, able to speak English, been taking HAART over	<p>Not reported</p> <p>Adherence was described as a reminder of illness and death (belief that God would keep them alive if</p> <p>The study identified three themes to describe the experience of adherence to HAART medication, these included i) commitment versus perseverance, feeling bad and healing helpers. Pills were positioned as reminders of illness, emphasising the importance of routine and adherence as an agent of survival. Describing a relationship with the pills.</p>

					6 months and willing to share experiences		they were non-adherent), as a relationship with the pills and negotiated by routine. Response to medication was also an important factor, where patients new an immediate response was felt they were more adherent (to insulin for example).
Kwinter (2005)	US	Depression	Semi-structured interviews	11	8 women and 3 men, over 18 years old, be using an antidepressant for depression for at least the past 4 months, engaged in	Not reported	Adherence was embodied through experiences of stigma, dependence, control, power and social system. Essentially describing adherence as  This qualitative study used in-depth interviews to describe adherence to antidepressant medication for people reporting a diagnosis of depression and attending non-physician counselling. The study identified themes of stigma and dependence, with participants describing antidepressants akin to insulin for diabetics in that 'it keeps you from dying'.

					psychotherapy with a non-physician and able to conduct the interview in English.		a social phenomenon, negotiated by social actors or institutions. Antidepressants were described as preventing 'feelings' being dealt with appropriately whilst on medication.
Lau et al. (2008)	Canada	Osteoporosis	Mixed focus groups	37	Post-menopausal women using at least one prescription for over-the-counter product for osteoporosis, could speak English, cognitively impaired or unable to manage medication	Not reported	Adherence is mediated by a number of factors, most notably relationships with healthcare professionals, administration requirements and routine, and knowledge about the medication and disease  This study used a mixed phenomenological approach to identify strategies to improve adherence, these were i) belief in the importance of medication adherence ii) medication specific factors iii) beliefs about medication and health iv) relationships with HCP v) information exchange and vi) strategies to improve adherence, which including sub-themes of using systems of adherence, using cues and reminders, understanding why medication is taken, regular follow-up and monitoring. Concluding that strategies to improve adherence should be individualised.

Mohammad pour, Nasrabadi and Nikbakht (2010)	Iran	HAART /HIV	In-depth semi-structured audio-recorded interviews and observations field notes	19	Hospitalised patients in the infectious diseases ward in varying organisations in Iran. 11 men and eight women, aged 27-52 years	Interpretive	The study identified four themes i) choosing to live, ii) strategies for adherence iii) relationships with HCP and iv) medication as motivator.	The study used IPA to investigate the experiences of adherence to highly-active anti-retroviral therapy for the treatment of HIV in Iran. The study recruited 19 participants over 15 years old with clinical evidence of HIV infection, the ability to communicate verbally and a willingness to participate with varying degrees of education level. Data was collected through semi-structured interviews and field notes and analysed using thematic analysis. The researchers did not justify why particular 'topics, issues, concerns or events' were selected for a more detailed interpretation and go on to describe a systematic rather than flexible approach. The study identified four themes i) choosing to live, ii) strategies for adherence iii) relationships with HCP and IV) medication as motivator. The studies provide short quotes to support their arguments however go on to make recommendations around nurses' involvement in decision making which does not appear to be in the data. Unfortunately the text goes on to describe the limitations of the study from a positivist theoretic perspective (few participant, not generalizable) rather than emphasising the rich data that the study collected. Additionally, the discussion does not make any reference to the 'ongoing' nature of adherence which is alluded to in the conclusion.
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Muir-Cochrane et al. (2006)	Australia	Mental health	Semi-structured interviews	10	16-24 years old (3 male, 5 female (page 165?)), homeless, have experienced mental health problems, could speak English and were willing to participate	Not reported	Adherence was described under the themes of i) obtaining medication ii) managing medication iii) adverse effects of medication and iv) interaction with illicit drugs	A qualitative study that presents adherence in homeless young people as part of their daily struggle. It's finding conceptualise medicines adherence as a social phenomenon however the authors do not state this, rather their findings are presented as discrete themes of obtaining medicines (medicines as currency and financial), managing medicines (smaller packs, keeping medicines at friends/relatives' houses), adverse effects (drowsiness is incompatible with a lifestyle where one's day is consumed with finding food, shelter and safety) and illicit drug (making their symptoms worse, being out of it). The study reports that the experiences of young homeless people adhering to mental health medication is a similar experience of adherence to other medicines in other populations.
Naidoo, Dick and Cooper (2009)	South Africa	Tuberculosis	Pre-interview questionnaire, interviews between 60-120 minutes	15	Purposive sample of spread of men, women, 18-57 years, recruited from a deprived clinic. Patients with psychiatric disorders, AIDS or HIV were	Husserlian	the authors did not report a description of the experience of medicines adherence but reported the two major themes of their findings "i) contextual, individual and disease factors associated	Medicines adherence to tuberculosis treatment in South Africa is a complex, multi-faceted experience that is largely influenced through psycho-social and individual, disease specific factors, e.g. symptoms. The study used 15 qualitative interviews with men and women using treatment for tuberculosis.

					excluded		with illness experience and ii) psychosocial factors related to adherence to tuberculosis treatment"
Nguyen et al. (2012)	Vietnam	HIV	Qualitative interviews (as part of a longitudinal study)	15	Women with HIV, average age 29 years old	Not reported	Adherence to antiretroviral therapy is argued as a social phenomenon of morality. Giving women their 'morality back' and avoiding 'morally bad' behaviour such as deviance from social norms  Qualitative interviews with 15 Vietnamese women using anti-retroviral therapy for HIV infection. The study positions adherence as a social phenomenon of morality. With adherence to medicines considered 'good' as it enables social norms, as well as prescriptions, to be adhered to and prevents 'a bad death'. Fulfilling socially normal roles such as a 'good wife' or a 'good mother' described adherence as social. The authors argue for medication regimes to better fit within the social lives of these women.
Sale et al. (2011)	Canada	Osteoporosis	Interviews	21	6 male, 15 female, aged 65-88 years old, low BMD,	Giorgi	Adherence was based on decisions mediated by the relationship with a healthcare  21 at high risk of fracture and taking medication for osteoporosis were interviewed to gain an insight into their experience of adherence. Decisions to take medication were mediated by the patient's relationship with their healthcare professional and were embodied by a risk-benefit analysis. Adherence was reported as a dynamic process which was continually changing, based on

							provider and based on a risk-benefit analysis and was dynamic, changing over time.	perceived risks and benefits.
Sanders and Van Oss (2013)	America	Older adults	In-depth interviews	149	70 years old, no gender data reported,	Not Reported	No 'essential' description is given however the authors state that medication-taking which is embedded within daily routines serve an aid to adherence.	This qualitative study investigated strategies to improve adherence by asking participants 'how' they adhered to their medicines. Students conducted 149 interviews and data was analysed thematically using deductive coding established a priori. Data was also analysed quantitatively to deliver statistical insights. The authors conclude that patients embed medicines adherence in task-based routines such as 'putting my rings on' or 'putting the coffee on' which, if disrupted, can disrupt adherence. The authors also reported that more than 50% of the participants required assistance with medication adherence, and the most common locations for storing medications were the kitchen and bathroom.
Scherman and Lowhagen (2004)	Sweden	Asthma/ Allergy	In-depth, face-to-face interviews	30	14 women and 16 men, between 18-62 years old, histories of symptoms and a positive skin test, range of socio-demographi	Giorgi Phenomenogra phy	The authors did not report a descriptions but presented the themes from their analysis which included i)access to medicines voices	This longitudinal study investigated adherence in patients with symptoms of asthma or allergy over eight years. N=30, interviews were conducted and identified several themes; which included i)access to medicines voices discomfort and fear ii) body damage without cure (including a) becoming immune, b) self-healing is weakened c) bodies signals camouflaged d) stigmatised) and iii) medicines as commercial objects not aiming to cure. The authors aimed to discover if experiences of medicines changed over time and the authors

					c backgrounds		discomfort and fear ii) body damage without cure (including a) becoming immune, b) self-healing is weakened c) bodies signals camouflaged d) stigmatised) and iii) medicines as commercial objects not aiming to cure	conclude that experiences of medicines can be stable and so clinicians must engage with patients to reach an agreement on how medicines should be used.
Seng and Holroyd (2013)	USA	Headaches	Interviews	21	Mixture of male and female with varying symptoms of headache who had been prescribed at least one acute headache medication	Not Reported	Optimum adherence to acute headache medication required a number of different behaviours and consequently was part of a complex experience mediated by a	This study investigated the behaviours involved in optimum use of acute headache medication. Adherence of 'when required' medicines is often difficult to conceptualise and so optimum use is often substituted. The study calls for better measurement and interventions to improve medicines use for acute headaches and concludes that behaviours involved in adherence/optimum use are many and varied, frequently interlocking to provide a milieu of optimum use. The themes identified by the study were These included i)lack of knowledge ii) forgetting iii) self-diagnosis iv) adverse effects v) inefficacy vi) access vii) role viii) social influences ix) preference alternative treatment. The study also identified cross-episode

number of facilitators and barriers to adherence. These included i) lack of knowledge ii) forgetting iii) self-diagnosis iv) adverse effects v) inefficacy vi) access vii) role viii) social influences ix) preference alternative treatment. The study also identified cross-episode (i) accessible, ii) communication iii) limiting therapy) and episode specific behaviours (self-diagnosis, medication (i) accessible, ii) communication iii) limiting therapy) and episode specific behaviours (self-diagnosis, medication choice, time, alternative therapy, repeat administration). Whilst the findings of the study are complex and give us insight into the experiences of medicines adherence to acute headache medicines, the difficulty is transferring these findings into a practical application for practice or further research.

choice, time, alternative therapy, repeat administration ).

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Sidat, et al. (2007)	Australia	HIV/AIDS	in-depth interviews	10	7 male and 3 female, with 100% adherence to HAART recorded more than six months ago	Not reported	The following issues emerged from the analysis i) readiness to start HAART ii) HAART as a life-line iii) 100% adherence as living longer and healthier iv) relationship with HCP v) coping/lack of adverse effects vi) improved clinical	10 participants that had recorded 100% adherence to HAART in the previous six months were interviewed and the data analysed phenomenologically. The interviews revealed that adherence is associated with longer and better life and that an ongoing relationship between the patient and physician, coping and a lack of adverse effects, as well as an improved clinical outcome (measured by T-cell counts) is needed to establish 100% adherence. The authors conclude that whilst 100% adherence may be attained, it might not be permanent, due to the ongoing and dynamic nature of treatment.
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outcome

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Tadesse et al. (2013)	Ethiopia	TB	in-depth interviews	26	11 male and 15 female, between 18-50 years old with TB accessing DOTS clinics	Not reported	Adherence was described as mediated by geographic access to medicines, concomitant financial burdens, traditional healing practices, access to social support and quality of health services.	This qualitative study highlights the complex nature of tuberculosis treatment in Ethiopia. Geographic and financial access to services most influenced compliance. The authors support a decentralisation approach to delivering services to enable a great population geographic (and financial) access to medicines.
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Tilden et al. (2005)	Australia	Diabetes	case study	1	26-year old female with early onset type 1 diabetes	Giorgi	<p>The experience of adherence is integral to the acceptance or rejection of self-identity.</p> <p>In this case study the participant, a 26-year old female with early onset insulin-dependent diabetes, was underwent 9 sessions of cognitive analytic therapy. The sessions were audio-recorded and transcribed and the psychotherapist kept a reflexive journal. The data for the study was made up of the transcribed sessions and the reflexive journal. These were analysed using a phenomenological approach. This identified two major themes i) rejection of the diabetic identity and ii) integration of the diabetic identity. In the case study it is possible to see how a patients sense of self dominates the experience of adherence, when this participants sense of self was poor her adherence was poor however as the participant integrated her diabetic self with her own sense of self and this contributed to an improved experience of adherence. It is difficult to assess the quality of the case study as most quality appraisal tools are based on the quality indicators of research using interviews or focus groups, rather than individual case studies.</p>
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**Table 8. Systematic Review Search Methodology and Excluded Studies**

Database	Search Terms	Years	Number of Hits	Excluded at Screening	Included
CINAHL	MH 'Medication Compliance' AND phenomenolo g*	2002-2014  Academic Journals	33	4 Dissertations 2 not including patients' experience; Bender et al. (2011) Jones et al. (2002)  11 not about experiences of medicines adherence Cardoso et al. (2013) Watts et al. (2002) Okumdi et al. (2013) Wang et al. (2014) Anderson et al.( 2010) Barnes et al. (2012) Martin et al. (2009) Anthony et al. (2008) Mosack et al. (2009) Chapman et al. (2004) Deegan et al. (2005)  2 not in adults Mawn et al. (2012) Chen et al. (2010)  Not in English Castro et al (2012)	13
MEDLINE	"adherence or concordance or compliance" AND "phenomenol ogy*"	1980-2014 in English, Adult (19 years+	126	93 excluded not about experiences of medicines adherence Suttanon et al. (2012) Dean et al. (2005) Hyland et al. (2014) Abbasi et al. (2014) Mudge et al. (2006) Haas et al. ( 2012) O'Brien et al. (2010) Meis et al. (2014) Hinckley et al. (2014) Usher et al. (2013) Ebert et al. (2014) Aakhus et al. (2012) Evangeli et al. (2014) Morgan et al. (2014) Mataix-Cols et al. (2002) Kilbride et al. (2013) Tovazzi et al. (2012) Norlyk et al. (2013) Petursdottir et al. (2010) Matwa et al. (2003) Li et al. (2013) Chapman et al. (2004)	18

Okumdi et al. (2013)  
Janes et al. (2013)  
Fitzpatrick et al. (2011)  
Hendry et al. (2012)  
Maclean et al. (1982)  
Hughes et al. (2011)  
Schuler et al. (2012)  
Richardson et al. (2010)  
Larsson et al. (2010)  
Peters et al. (2012)  
Flament et al. (2001)  
Watts et al. (2002)  
Carolan et al. (2012)  
Garnweidner et al. (2012)  
Cianci et al. (2011)  
Falter et al. (2006)  
Matthew et al. (2011)  
Badlan et al. (2006)  
O'Brien et al (2008)  
Porter et al. (2005)  
Smith et al. (2007)  
Benisovich et al. (2003)  
Hale et al. (2010)  
Sale et al. (2010)  
Mgutshini et al. (2010)  
Eldh et al. (2004)  
Walsh et al. (2000)  
Holmstrom et al. (2005)  
Whetstone et al. (1991)  
Sloan et al. (2009)  
Costain et al. (2008)  
Kinder et al. (2009)  
De Geest et al. (1994)  
Porter et al. (2007)  
Rasmussen et al. (2007)  
Thomas et al. (1993)  
Anthony et al. (2008)  
Dickerson et al. (2007)  
Zubenko et al. (2000)  
Johannesen et al. (2008)  
Barnas et al. (1985)  
Kim et al. (2007)  
Hinson et al. (2005)  
Niehause et al. (2005)  
David et al. (1990)  
Bates et al. (1993)  
Miller at al. (1993)  
Eldh et al. (2006)  
Fogel et al. (1992)  
Fu et al. (2005)  
Olesen et al. (1990)  
Voruganti et al. (2006)  
Masand et al. (2006)  
De Oliveira et al. (2006)  
Tunstall et al. (2000)  
O'Toole et al. (2004)  
Gibson et al. (2004)

				<p>Roberts et al. (1995) Wyatt et al. (2003) Forsyth et al. (2000) Beich et al. (2002) Bach et al. (1996) Carlson et al. (1998) Anstett et al (1980) Sheikh et al. (1995) Thomas et al. (1994) Larkin et al. (1982) Kugelmann et al. (1983) Jenkins et al. (1988) Schwoon et al. (1980) Courtemanche et al. (1989)</p>	
				<p>5 not about patients' experiences Fleming et al. (2013) Sissolak et al. (2011) Mercier et al. (2011) Hansen et al. (2009) Svedberg et al. (2001)</p>	
				<p>8 duplicates Naidoo et al. (2009) DeMoss et al. (2014) Mohammadpour et al. (2010) Enriquez et al. (2004) Scotto et al. (2005) Seng et al. (2013) Sidat et al. (2007) Karamanidou et al. (2014)</p>	
				<p>2 not in adults Grossoehme et al. (2014) Cheung et al. (2012)</p>	
PsychInfo	"DE treatment compliance" AND "DE phenomenology"	2009-2014	4	<p>1 duplicate Mohammadpour et al. (2010)</p> <p>1 not about experiences of medicines adherence Neal-Barnett et al. (2010)</p>	2
Sociological Abstracts Online	"medicines compliance", "medicines concordance", "medicines compliance" and "phenomen**"	1983-2009	9	<p>6 not about medicines adherence Inclan (2005) Snortum (1988) Jones (2005) Strong and Huon (1998) White (1983) Pless (1984)</p>	3

EMBASE	SH "Medication Compliance" and SH "phenomenology"	Human, In English, Not MEDLINE	1	Duplicate DeMoss et al. (2014)	0
Web of Science	"medicines adherence", "compliance", "concordance", , "phenomenological"	All years	54	36 not about experiences of medicines adherence Nolan (2013) De Portugal (2013) Peters et al. (2012) Aakhus et al (2012) Schuler et al. (2012) Haas et al (2012) Falter et al. (2012) Sissolak et al. (2011) Crawford et al. (2010) Chen et al (2009) Goodwin et al. (2008) Orfei et al. (2008) Johannesen et al (2008) Kim et al. (2007) Rasmussen et al. (2007) Voruganti et al. (2006) Hansen et al. (2006) Niehaus et al. (2005) Gibson et al. (2004) Wyatt et al (2003) Mataix-Cols et al. (2002) Forsyth et al. (2000) Walsh et al (2000) Carlson (1998) Newport and Nemeroff (1998) Bach et al. (1996) Barnes et al (1995) Roberts et al. (1995) De Geest et al. (1994) Solway et al. (1991) David (1990) Schwartz et al (1985) Mason et al. (1984) Lieberman et al. (1984) Kinston (1983) White (1983)  1 Not investigating patients experiences Pirie et al (2007)  5 not in English 박정원; 임화윤 (2012) Song (2011) Maeda et al. (2009) Teike-Luthi (2007) Strydon et al. (2000)	5

7 duplicates excluded  
Evangelini et al. (2014)  
DeMoss et al. (2014)  
Seng et al. (2013)  
Parnas et al. (2013)  
Sale et al (2011)  
Hansen et al (2009)  
Keck (1996)

## The Epoché

Epoché or 'bracketing out' of preconceived ideas about medicines adherence relates to Chapter 4. The text is presented in the first person and is included to demonstrate the adoption of the epoché process within the study. The text was used during the analysis to scrutinise the codes produced and provides an insight, and summary, of *a priori* opinions and beliefs about medicines adherence. Epoché was practiced informally prior to interviews, focus groups and analysis and was regularly referred to throughout the analysis to recognise themes that may have been projected onto the data based on previously held beliefs.

“My current understanding of adherence is dually framed; the first, but by no means more significant framing, is based on my career and education in the natural sciences paradigm. A formal, scientific presupposition of adherence exists that links back to my formal education and professional career. Indicated for particular diseases, at particular dosages each therapeutic regimen is evidenced and validated by evidence-based medicine. Fundamentally adherence to medicines is governed by the physical characteristics of the medicine, its container and the patient's ability to understand and execute the prescription. Pharmacists are educated to consider the following in relation to adherence; how will the patient open the container? Does the patient like the taste? Can the patient feel the benefit of the medicine? These questions fundamentally identify medicines as objects, and thus medicines adherence, is intrinsically linked to the physical characteristics of those objects. Additionally, medicines taking might be considered more as an action, the execution of an order rather than a self-motivated behaviour. Patients often appear to reject orders out-rightly or do not understand how the prescribed order should be carried out. Often adverse effects stop patients taking their medicines, if they feel dizzy, sleepy, nauseous or have gastrointestinal disturbances. Patients sometimes simply forget to take their medicines in the same way that we forget to do other things. Sometimes it is linked to routine behaviours, so that patients just take their medicines without really thinking about it or knowing why or what the medicine is for. Sometimes patients are addicted to the medicine and so they're non-adherent because they take more than they should or they're afraid of addiction to the medicine and don't want to be addicted anymore so then they stop the medicine abruptly.”

# Analytic Process

Analysis Extract 1 below demonstrates manual coding, as transcript text became codes

CONFIDENTIAL

us and I used to be a motor mechanic you see when I started off, for a lot of year, so in contact with, obviously asbestos but he said actually, for somebody, being, living in this area, he said, you've got some like lesions, but I don't feel there is a need for any medication or any invasive operations or anything, so I think it's just a case of hoping they don't develop further but we'll have to just wait and see

[whooshing noise]

*Medicines prescribed as a reaction to unusual side effects.*

**Your snow has just fallen off your conservatory!?**

*Social / TRUST  
BAD FAITH*

so yeah, I think I accept me medication as, I'm trusting me doctor and I'm trusting the people who have done the operation, because I'm a funny bugger like that, when they were taking us down, just before they put us under, they said, I wondered if you'd tell the surgeon, tell him to have a good day would you [laughing] working on motor cars you do have bad days where everything is falling off and you think woah I've made a mess of that, but erm, no. So, let's see, my erm, experience, I mean it may have nothing to do with this, but my experiences erm, with James Cook have been really, really good, you know the nurses, basically everybody I've met has been very good.

**You mentioned going from ordinary to a big load of medicines, what did you mean by that?**

*"Just painkillers ordinary medicines  
Personalised*

Well... when I did the, when I had me back thing, I erm, I was on just pain killers and erm..... oh co-, like a co- it was in the codeine family

**Co-codamol?**

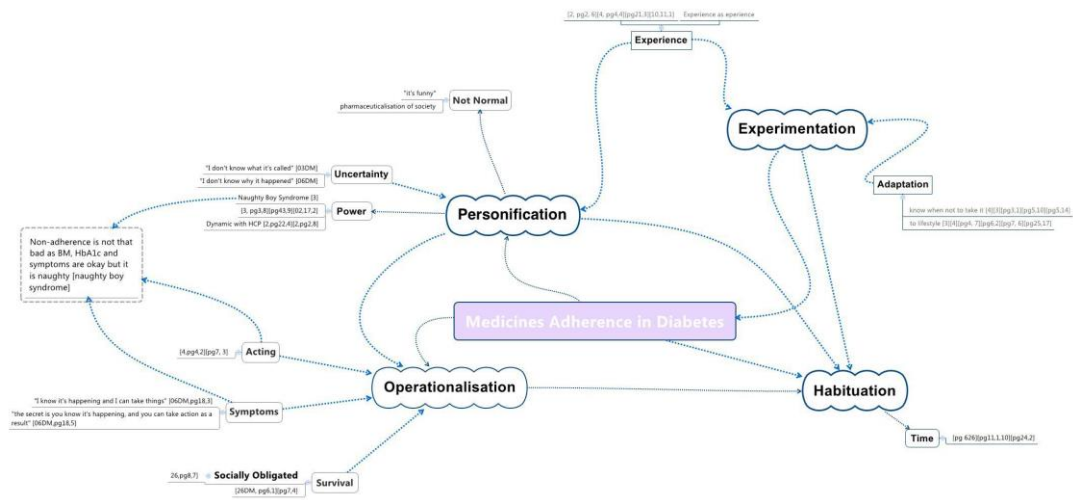
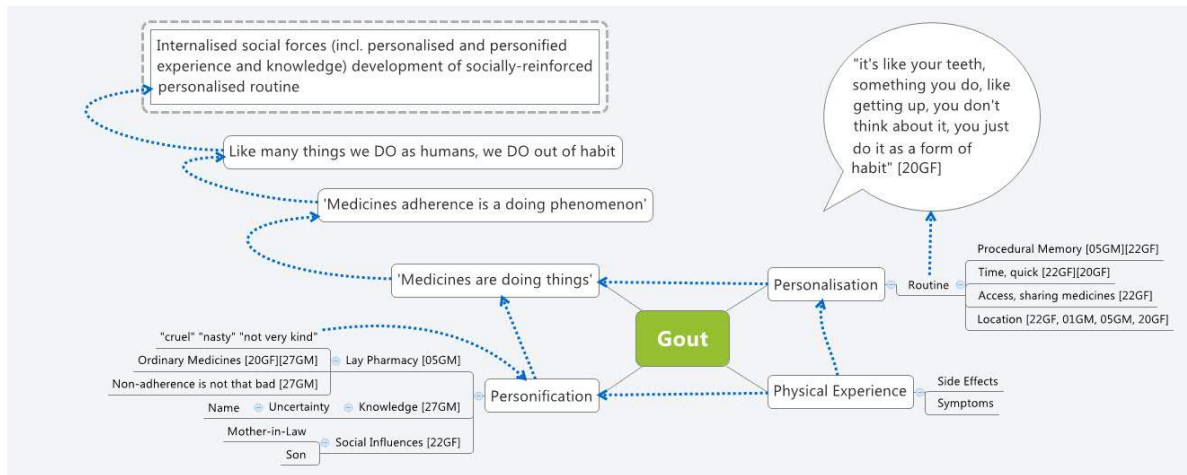
*She mentioned non-adherence*

Co-codamol. And me doctor said well, you know I think I took two, at night, something like that, and he said I'd like, you know, see how it goes but I'd like to ween you off it though because they can become addictive, yeah, erm... so I basically got off that, and actually, when I had me heart thing, and we were doing the six weeks rehab in James Cook, one of the nurses, Aurora, tallish girl and a small girl, I've forgot her name now, a pharmacist person came in and he advises, any mild pain... erm, medication, the best thing I would advise you, is erm.... [tapping] paracetamol. It's the one least likely to give you any side effects and do you any damage kind of thing, but it will also give you pain relief as well, and that was his thing that if anybody had any sort of painful things, that but I think that was when if you might say, when I went onto the increased, intake, it was with the heart, and the things that go along with that, sorry, one in the morning, I take two aspirin, I'd have to get me thing down, erm...

*transference or risk: benefit model that HCPs use.*



Analytic Extract 3 and 4 demonstrate how headline themes were formalised.



## Appendix B: Study materials

### Participant Pack



## A phenomenological investigation in patients' lived experiences of medication adherence

### Participant Information Sheet

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#### ***Who are we?***

The Chief Investigator is Adam Pattison Rathbone. He is a full-time PhD student at Durham University supervised by the senior research team Professor Andrew Husband, Dr Adam Todd, Dr Kimberly Jamie and Professor Pali Hungin. Adam will conduct the interviews and focus groups and will be the main contact for the study.

#### ***Why are we doing the study?***

The study is trying to find out what patients experience when they take medication for certain diseases or conditions. This will help healthcare professionals have a better understanding of what it is like for patients to take medication and be able to improve the experience in the future. This study is trying to document exactly what patients experience whilst taking medicines and if the experience differs between different groups of patients with different disease. For example, a patient taking medicines for high blood pressure might have a different experience to patients taking medicines for diabetes. This study is not trying to find out if you do or do not take your medicines; all we want to know about is your experience of taking medication.

***Do I have to take part?***

No. You do not have to take part if you do not want to. If you decide you want to take part in the beginning and then change your mind halfway through, you can leave the study. You don't have to explain why you want to leave. If you decide not to take part or withdraw halfway through your care will not be affected. If you do decide to take part, you will be asked to sign a consent form before we start (a sample form is given below for you to become familiar with).

***What will happen during the study? What is a focus group?***

A focus group is when 5-8 people sit together in a group and talk about something. In this focus group, I'll tell you about what we've found from some earlier research into how people take their medicines and then we'll talk about it. We'll also be discussing ideas about how to help people take their medicines as prescribed.

***Who else will be in the focus group?***

Other people in the focus group may have already been interviewed as part of the earlier research or they may be new to the study. Either way, the views and opinions of all participants are important and just as valued.

***What happens after the study?***

After the focus groups, we will look at what everyone has said and produce a report. The report, or parts of it, will be presented at conferences and published in scientific journals. Your personal details will never be published and you will not be identifiable in any of the publications.

***Are there any risks or downsides to taking part?***

It is very unlikely you will come to any harm from taking part in the study. Your emotional and physical needs will be considered thoroughly. If you are concerned about your welfare or no longer want to take part in the study you are free to leave at any point.

***What are the benefits of taking part?***

Although there will be no direct benefit to you, by taking part in this study you will be helping healthcare professionals get a better understanding of patients' experiences of taking medicines in the future. This may lead to better ways of taking medication or technology to help people take their medication more easily.

***What happens if I change my mind and no longer want to take part?***

If you change your mind all you need to do is inform a member of the research team at any point during the focus group and you will be withdrawn from the study. However, we would keep any information we had collected up to that point and use it as part of the research.

***What if I'm not happy with the way the interview or focus group goes?***

Firstly, I'd like you to tell me, however if you would prefer you can contact a member of the supervisory research team, Dr Adam Todd or Professor Andy Husband on 0191 334 0542, or the Chair of the School Ethics Committee, 0191 334 0210 There will not be any compensation arrangements in the unlikely event you are harmed during the study. If you are harmed during the study and it is due to negligence you may have grounds for legal action, which you may have to pay for.

***Who is paying for this research?***

Durham University in collaboration with AstraZeneca (a company that manufactures medication). Durham University in collaboration with AstraZeneca (a company that manufactures medication). AstraZeneca are not directly involved in preparing any documentation or shaping the research other than in a review capacity. AstraZeneca are asked to review documents and offer advisory comments – this enables the school to take advantage of the wealth of research experience within AstraZeneca. AstraZeneca will not receive or have access to the study data. The contract with AstraZeneca ensures full freedom for the team to publish the academic results of the research.

***Who will see information about me?***

If the Chief Investigator suspects you are a danger to yourself or to others, or you confess to serious crime (e.g. murder) or significant misuses of medication (e.g. giving adult medication to children) confidentiality will be broken and the relevant authorities informed. Otherwise, only I (the Chief Investigator) will see your personal information. Once you have agreed to be part of the study you will be given a unique code. All of the information we collect will be coded throughout the study and this will stop you from being identified. The only piece of information that will have your name on it, the consent form and 'registering an interest' form, will be kept under the control of Chief Investigator, under lock and key at the

Holliday Building, Queen's Campus, Stockton-on-Tees. At the end of the study, the consent forms and 'registering an interest' form will be destroyed. AstraZeneca will not see any personal information about you.

***Who is checking what you're doing is right?***

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South-Central Oxford C Research Ethics Committee. Durham University Ethics Committee, AstraZeneca Research and Development Team and senior researchers from Durham University have also reviewed the protocols that will be used during this study.

***What do I do now?***

If you want more information please contact me on 0191 334 0368 or [a.p.rathbone@durham.ac.uk](mailto:a.p.rathbone@durham.ac.uk) or write to me at the address below. If you want to take part in the study please fill out the 'Registering an Interest Form' below and send it back to me in the stamped addressed envelope and I will contact you to arrange the interview. If you'd prefer not to take part in the study, simply do not respond to this letter.

For your additional information, here are the names and contact details of the Research Team involved with the study:

Mr Adam Pattison Rathbone  
 Chief Investigator  
 School of Medicine, Pharmacy and Health  
 The Holliday Building  
 Queen's Campus  
 Durham University  
 Teesside  
 TS17 6BH  
 Telephone 0191 334 0368  
 Mobile 07904 220720  
 Email [a.p.rathbone@durham.ac.uk](mailto:a.p.rathbone@durham.ac.uk)

Prof Andy Husband  
 Dean of Pharmacy (address to The  
 Holliday Building)  
 E-mail: [a.k.husband@durham.ac.uk](mailto:a.k.husband@durham.ac.uk)  
 Telephone: 0191 334 0102

Dr. Adam Todd  
 Senior Lecturer in Pharmacy Practice  
 (address to The Holliday Building)  
 Email: [adam.todd@durham.ac.uk](mailto:adam.todd@durham.ac.uk)  
 Telephone: 0191 334 0542

Prof APS Hungin  
 Director in the Centre for Integrated  
 Healthcare Research  
 Head of School & Dean of Medicine  
 (address to The Wolfson Building)  
 Email [a.p.s.hungin@durham.ac.uk](mailto:a.p.s.hungin@durham.ac.uk)  
 Telephone: 0191 334 0375

Dr Kimberly Jamie  
Lecturer in Sociology  
School of Applied Social Sciences  
Durham University

32 Old Elvet  
Durham  
DH1 3HN  
Email: kimberly.jamie@durham.ac.uk  
Telephone: 0191 334 1478



Please complete and sign this form and post it back to us in the enclosed stamped addressed envelope. Please complete this form in **BLOCK CAPITALS**. Your details will be managed confidentially and destroyed at the end of the study. Thank you.

**Contact Details Sheet**

Name (what you'd like us to call you):	
Gender	
Address:	
Age	
Occupation	
Telephone Number:	
My main diagnosis is (please circle or add diagnosis as appropriate);	<b>COPD (bronchitis or emphysema)</b> <b>Cardiovascular Disease (including high blood pressure or heart problems)</b> <b>Gout</b> <b>Cancer</b> <b>Diabetes (type I or type II)</b>
Best time to contact you:	
"By signing this form I am confirming that I want to be contacted to be involved with	



the study looking into experiences of medicines adherence”	
Signature:	
Date:	

## Participant Consent Form

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Please initial the boxes to confirm you agree with each statement

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my legal rights, or care being affected. I understand that any information collected up until the point of my withdrawal will be kept and used as part of the research.

3. I understand that by taking part in this research, this consent form and ‘Registering an Interest’ Form will be stored at Durham University under the direction of the Dean of Pharmacy.

4. I understand I will take part in a focus group and the focus group will be audio recorded.

5. I agree to the use of my anonymised quotes when this research is published.

6. I am willing to be contacted by the research team in the future regarding this project.

7. I agree to take part in the above study.

Name of Participant:

Name of Researcher:

Date:

Date:

Signature:

Signature

## Risk Assessment

Please complete the following for your study. This form must be dated and signed by the Principal Applicant. Please describe the risks for both participants and researchers. Please note that all hazards relating to risk of injury/harm will be forwarded to the Health and Safety Officer for the School of Medicine and Health

**Location:** Participants' home

**Activity:** Interviewing participants

Hazards	Those at Risk	Description of Risk	Risk Controls	Risk Rating
Working in the community	Researcher	Interviewing participant in their own home	<p>Interviews will always be undertaken in daylight hours</p> <p>The research team will be informed when and where an interview will take place including interview times. The interviewer will contact a member of the research team immediately before initiating the interview and immediately after. If the interviewer fails to contact the research team when scheduled, the interviewer will be contacted by telephone by a nominated member of the research team – if there is no answer after three attempts, the emergency services will be called.</p> <p>A fully charged mobile phone will always be taken to the interviews. This will contain contact details for members of the research team. The interviewer will also have a unique code phrase that can be used to alert the research team that assistance is required without drawing attention.</p> <p>Durham University identification will be carried to each interview.</p>	Low
Asking patients/informal carers about their experience(s) of taking medication	Researcher	Interviewing a patient/carer about their experience of taking medication and becoming distressed	The research team will establish sources of support available while undertaking the project. The interviewer (which will be APR) has plenty of experience of interviewing patients and asking about their medicines taking behaviour. This experience will be invaluable while interviewing patients for this study. Additionally APR has attended Durham University interview training and will attend Oxford University training sessions on using interviews in qualitative	Low

			research. APR is seeking support from qualitative researchers (HH, HC), who have extensive experience of interviewing patients. APR will be supported by AH and AT who have a wealth of experience of interviewing patients.	
Asking patients about their experience(s) of taking medication	Patient	Patients becoming distressed during and after the interview	<p>If a patient became distressed we would ensure that this was brought to the immediate attention of Dr Husband or Prof Hungin (and/or Dr Lisa Banks) who are senior members of the research team.</p> <p>The participants will be interviewed at home and it may be unusual for patients to be interviewed about their medicines in this setting, however all of the interview questions will be open-ended so the participant will be in control of the information they wish to disclose. Additionally if the patient does become distressed, there are likely to be things at home that will reassure and support them. Participants will be advised at the beginning of the interview of their right to withdraw and how the interview will end if they become distressed. The participant information sheet specifically states that the interview will focus on the patient's 'experience' of hospice care and no advice or guidance will be given from the researcher regarding the patient's medicine. We will make it clear to the patients that they are participating in a research project and not a clinical review of their medication. In addition to the participant information containing this advice, we will also re-affirm this with the patient immediately before the interview takes place.</p> <p>Any distressed patient will always be given the opportunity to withdraw from the project. After the interview, patients will also be left with a 'support sheet' that contains the contact information of support groups and the contact details of the research team to get in touch if they wish.</p>	Low

**Risk Rating = Likelihood x Severity = LOW, MEDIUM or HIGH**

**Assessor Name (Principal Applicant):** Adam Pattison Rathbone

**Signature:** 

**Date:** 01.12.2013

## **Section 2: Indemnity and Insurance Arrangements**

**INSURANCE:** please confirm that a copy of the application form has been lodged with the University's Insurance Officer: [where, for example: application is made to an external ethics committee/organisation, including an NHS Ethics Committee; where a project is likely to fall outside or require an extension to the University existing insurance cover, (full details are available at: <http://www.dur.ac.uk/procurement.office/>) where there is some significant Risk involved, or where a funder/sponsor requires a particular insurance policy to be in place.] and that adequate insurance cover is in place for your study.

**Yes**

If no please explain:

**INDEMNIFICATION:** please state below any special arrangements for indemnification in the event of injury and non-negligent harm to the participants.

If not applicable please add not applicable below.

**Not applicable**

## Institutional Ethics Approval Letter



Shaped by the past, creating the future

**Rebecca Maier**  
Research, Development and Trials Manager  
Chair, School of Medicine, Pharmacy and Health Ethics Sub-Committee

**Adam Rathbone**  
PhD Student  
School of Medicine, Pharmacy and Health  
Durham University

8<sup>th</sup> April 2014

Dear Adam,

**Re: Ethics Application ESC2/2014/03**  
**A phenomenological investigation into patients' lived experiences of medicines adherence**

Thank you for sending the above application to the School of Medicine, Pharmacy and Health Ethics Committee for ethical review. The project was reviewed at a committee meeting on 19<sup>th</sup> February 2014. The committee requested some changes to the application, and these have now been reviewed by myself as Chair. I am satisfied that all of the comments made by the committee at the meeting have been adequately addressed and I can therefore confirm Durham University ethical approval for the study.

Approval is given subject to the following:

- That you gain all relevant NHS REC, governance and Caldicott Guardian approvals prior to starting the research.
- That data generated for this study is maintained and destroyed as outlined in this proposal and in keeping with the Data Protection Act.
- If you make any amendments to your study, these must be approved by the School committee prior to implementation.
- At the end of the study, please submit a short end of study report (ESC3 form) to the School ethics committee.

Please do not hesitate to contact me should you have any questions.

Kind regards,

A handwritten signature in cursive script that reads "R Maier".

Rebecca Maier

## NHS Ethics Approval Letter



### Health Research Authority

#### NRES Committee South Central - Oxford C

Bristol REC Centre  
Level 3, Block B  
Whitefriars Building  
Lewins Mead  
Bristol  
BS1 2NT  
Telephone: 01173 421383

06 May 2014

Mr Adam Pattison Rathbone  
Research Postgraduate  
Durham University  
The Wolfson Building  
Queen's Campus  
Stockton-on-Tees  
TS17 6BH

Dear Mr Rathbone

**Study title:** A phenomenological investigation into patients' lived experiences of medication adherence  
**REC reference:** 14/SC/0272  
**IRAS project ID:** 145439

The Proportionate Review Sub-Committee of the NRES Committee South Central - Oxford C reviewed the above application on 6th May 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Miss Lauren Allen, [nrescommittee.southcentral-oxfordc@nhs.net](mailto:nrescommittee.southcentral-oxfordc@nhs.net).

#### Ethical opinion

On behalf of the Committee, the Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the

A Research Ethics Committee established by the Health Research Authority

## Interview Schedule

Interviewer (Chief Investigator,) re-introduces himself as the researcher and thanks the participant for showing an interest in the study.

Recaps the study, reminding the participant what the interview is about and that we would like to chat about their experiences of taking medicines as they are prescribed. The participant is reminded that if the Chief Investigator suspects abuse; if they confess to serious crime (e.g. murder), significant misuse of medicines or if they indicate they are a danger to themselves or others the Chief Investigator is obliged to break confidentiality and inform the authorities, as outlined in the Participant Information Sheet.

Remind the participant that they will not be identifiable from the information that is collected and only the Chief Investigator will have access to the consent and 'registering an interest' forms with their names. Ensure the participant understands that this is an interview about their experiences of medicines taking and should not impact on how they take their medicines at all as this is not a clinical review. The interview will not impact on the care they receive and the information will not be shared with healthcare professionals involved in their care. Additionally, remind the participant that the interviewer will not be able to answer any questions about the patient's medical condition or medicines. Remind the participant that if they do not want to answer any of the questions that can say 'pass' and we will move on and that they can end the interview at any point by saying 'I'd like to end the interview now' or something similar. Additionally participants will be reminded that they can withdraw from the study up until the end of the interview or focus group. Ask the patient if they are still happy to be contacted via telephone in the future to discuss and confirm the findings. Re-confirm the participant's willingness to be audio-recorded and that they still want to take part. Go through the consent form and sign it.

"Now we're ready to start, how did you feel when you were diagnosed with....? "

*This will include the participant's experiences of being diagnosed with their condition; what happened when they were diagnosed and how it felt. This will lead onto the experience about first being prescribed the medication; how involved the patient was with the decision to start; faith or trust in the prescriber; knowledge about the disease; financial instability; loss of control and continue the medication/prescribing of the medicine; what they felt or believed then and if this has changed now*

"What are your experiences of taking your medicines as prescribed every day? "

*This will include positive and negative experiences; if they find it difficult or easy to adhere and may identify strategies used by the patient to adhere to their prescribed medicines; how they feel about their medicines and if this has changed over time*

“What, if any, are your experiences of not being able to take your medicines as prescribed?”

*This will include how these experiences have changed over the duration of the course of treatment. What strategies (if any) the participant uses to ensure they take their medication as prescribed, such as help from friends or relatives. This question will also identify how the patient felt if they were not able to adhere to their regimen and what they believed would happen*

“Is there anything that you’d like to add that we haven’t discussed?”

At the end of the interview, the participant will be thanked for their contribution and for their time and input and offer an opportunity for them to ask any questions. Additionally the patient will be asked if they would like to see the results of the study (if so they will be asked if they would like to receive them via email or via post). Participants will be given the ‘Information for after the interview’ sheet (see Post-Interview Information V1).

**Focus Group Schedule and Slides**


The Chief Investigator will introduce himself and the facilitator (this is expected to be a member of the senior research team or a Wolfson Research Institute Postgraduate Associate) and summarise the study to date. The Chief Investigator will present the findings of the study to date including potential interventions to improve medicines adherence. The Chief Investigator will then invite comments from the focus group about the findings, in a manner consistent with successful focus group technique (Crossley, 2002, Kitzinger, 1994, Morgan, 1996).

15/07/16

## Medicines Adherence Focus Group Presentation


A phenomenological investigation into patients' lived experiences of medicines adherence

Presented by Adam Pattison Rathbone  
7<sup>th</sup>, 9<sup>th</sup> and 16<sup>th</sup> November 2015



## What is medicines adherence?

- Describes "how patients use medicines in relation to how they're prescribed" NHS, WHO, DoH
- E.g. ONE tablet THREE times a day for 7 days




## What our research showed

- Patients get to know their medication (personification)
  - What the medicine is for
  - How the medicine works (lay pharmacology)
  - Particular places
  - Names
  - Particular ways of taking (after brushing teeth, before put kettle on)
- Prescriptions are personalised (personalisation)
  - Patients reported personalising their prescription based on what they saw, heard, read or were told
  - By healthcare professionals, family, friends, the TV, media, newspapers
  - By the medicines themselves
  - Leading to routine/habit formation




## Key Point

- Adherence is constructed through micro- and macro-social interactions with the pharmaceutical product (micro-social), healthcare professionals, the media, friends, family and wider society (macro-social)
  - I.e. adherence is like a 'culture', it just becomes part of everyday life, rather than an outcome



## What do you think?

- Have we hit the nail on the head?
- Have we missed anything?



## Developing adherence interventions



15/07/16

### Multi-compartment Compliance Aids

Durham University

### Educational interventions

- What the drug does?
- How it works?
- The importance of taking medicines
- Disease specific information
- Answering other questions

Durham University

### Reminder Devices

Durham University

Durham University

### Medication Reminder Charts

Durham University


### Simplification or a Polypill

Durham University


15/07/16

Other interventions?



- Adherence classes?
- Peer support groups?
- Online forums?
- Social media pass book?
- Pill Profile?



Does anybody have anything else they'd like to add?



Thank You





## **Appendix C: The ethics of studying adherence**

This chapter outlines some of the ethical tensions encountered during the study. This chapter outlines the practical solutions to some of the ethical issues of using qualitative research methodology to investigate medicines adherence before turning to consider the ethical tensions raised by studying adherence and being a registered pharmacist. This chapter finally describes some of the ethical conflicts related to adherence, the pharmaceutical industry and the pharmaceuticalisation of society. Despite the ethical issues described below, the project was reviewed and given favourable opinion by the Durham University School of Medicine, Pharmacy and Health Ethics Sub-Committee and the NHS Proportionate Review South-Central Oxford C Ethics Research Committee. Amendments were made to these approvals, which enabled participants for focus groups to be recruited through local academic and professional networks as well as through community pharmacies and general practices.

### **Practical ethical considerations**

Preparing the study for ethical approval meant considering the practical issues that might arise during everyday running of the study. These included obtaining consent from the participant to be involved in the study; maintain confidentiality and adhering to data protection laws; limiting and dealing with distress; giving participants the chance to withdraw from the study and recognising and managing disclosure of medicines non-adherence. Each of these issues had to be addressed as a matter of good research practice and how these issues were dealt with is documented below.

#### ***Consent***

Full informed consent was obtained before the interview or focus group began and participants were given copies of the consent form at the point of invitation to maximise the length of time for them to consider their options. If participants had not given consent to be included in the focus group prior to the interview, consent was taken only to be involved in the focus group at the focus group. Participants were able to withdraw at any time up until the end of the interview or focus group without giving a reason. Participants were informed in the Participant Information Sheet and at the beginning of the interview and focus groups that their decision to take part in the study would not affect their care in anyway. As the participants were first approached by their community pharmacy or

general practice team, it was possible that some participants may have felt that they were obliged to say yes to accept the invitation. In order to minimise the impact on the relationship between the community pharmacy or general practice teams and their patients, these teams were instructed to advise their patients to direct their questions about the study to the research team, whose contact details were within the Participant Pack. This prevented potential participants becoming confused about their community pharmacy or general practice team's involvement with the study and altering the patient-practitioner relationship. If the participant decided to take part in the study, the community pharmacy or general practice team would forward their contact details to the research team, or the patient would contact the research team directly. The community pharmacist or general practitioner assessed capacity initially when distributing Patient Packs and identifying patients for the study, as this is part of their routine work. To a certain extent, when participants contacted the research team directly, assumed capacity was taken. Prior to consent being taken at the beginning of the interview or focus group, the participants' capacity was also assessed.

#### ***Confidentiality and data protection***

Confidentiality was of paramount importance for this study and in all research and participants should feel reassured that their details would be kept confidential and only seen by a limited number of authorised members of the research team. Participants consent forms and 'Registering an Interest' forms were kept in a locked filing cabinet in a locked office at the Queen's Campus, Stockton. The consent form stated clearly that the consent form and 'Registering an Interest Form' will be kept under these conditions and access to this was restricted, even to supervisory members of the research team. Quotes have been anonymised in publications and sensitive information altered to protect participants' confidentiality – if quotes were edited to provide anonymity, any editorial changes were discussed by the research team and, where possible, with the participant to ensure the meaning of the quote was not changed. A secure password-protected computer was used to store electronic data (audio recordings and transcripts) and was kept under the supervision at all times. The transcript data collected from the study will be destroyed five years after the end of the study. AstraZeneca have not and will not have access to confidential participant information, such as names, address, date of births or contact details.

#### ***Distress***

Participants can become distressed during interviews if they feel under pressure to answer questions or to answer questions in a certain way. Participants in this study were reminded that they can withdraw from the study at any time without giving a reason simply by stating 'I would like to stop the interview now' or 'I would like to leave the focus group' or something similar. Additionally, if a participant did not want to answer a question they were able to say 'pass' and the interview moved onto the next question – participants were reminded of this before giving consent. As the questions were open-ended, the participant was in control of the detail that they gave and this allowed a sense of control for the participant and ensured an even balance of power in an attempt to limit distress. The research team had experience of speaking to patients about medicine taking behaviours and medicines adherence and this experience was utilised during the study to minimise distress to the participants. Interviews were paused if the participant showed signs of distress and offered the opportunity to pause, reschedule or terminate the interview. Participants were never left in distress and all participants were given a support sheet, entitled 'Support Information for after the study', this signposted participants to relevant areas of support, such as their local pharmacy and their general practitioner, if they felt the need to after the conclusion of the interview. Additionally this information advised the participant what to do if they were unhappy with how the interview went. If participants became or showed signs of distress during the focus group the session was paused, this gave participants the opportunity to recover themselves or withdraw from the focus group.

### ***Withdrawal***

As there were arguably two phases to this study (interviews and focus groups), participants were able to withdraw at the end of each phase, for example, if a participant was interviewed they did not have to take part in the focus groups. A practical approach to withdrawal was taken in that participants were able to withdraw from either the interview or the focus group at any time during the day of the interview or focus group. This meant participants had the opportunity to reflect on what they had said and contact the research team if they wanted to withdraw their data. After this point, it would be impractical to remove data as it would have been transcribed and coded and formed part of the overall analysis.

### ***Disclosure***

A broader ethical issue raised by this study was the possible disclosure of medicines non-adherence behaviours and how a researcher with registered pharmacist status would

negotiate this. During the course of this study that experience as a clinical pharmacist may lead to the identification of potentially hazardous medicines-taking behaviours or medicines use issues. Registered pharmacists have an ethical responsibility to aim to improve or alleviate the participant's medicines adherence issues (either directly or indirectly by referring the participant to their prescriber/family doctor). On the other hand however, the study context raised contention between the ethical responsibility of the identity of a researcher and the identity of a pharmacist. This is discussed in more detail in the section below and constitutes a paper published in *Sociological Research Online* (presented below) Unfamiliarity with the participants, not having access to appropriate medical notes and not having access to previous medication records or pharmacy records supported an argument that it would be unprofessional and inappropriate for any pharmacist to make clinical judgements pertaining to the severity of any identified medicines adherence issues in relation to the participants/patients overall package of health and pharmaceutical care. Furthermore, participants were invited to be part of the study and were advised that the study would not impact on their routine healthcare – if confidentiality was broken and the participant's usual healthcare team informed of a medicines adherence issue, this would breach the agreement between the participant and the research team, causing distress to both parties. In light of this, and after much consideration, I decided not to breach confidentiality and report medicines adherence issues that come to light during the interviews or focus groups. The support page left for participants after the interview or focus group titled 'Support Information for after the study' contained information about what the patient should do if they are worried they are not taking their medicines as prescribed and this was deemed sufficient to directly signpost participants to necessary support.

Despite a more hazardous disclosure occurring during the study, in the event a participant disclosed something else that was potentially hazardous, to either the participant themselves or another person in relation to the access or use of medicines, there was a plan to discuss this with the senior supervisory members of the research team, to consider the matter in a clinical, social, ethical and legal context, before attempting to discuss the issue with the participant. For serious clinical issues, the participant would be strongly advised that they should attend their GP surgery or their pharmacist to discuss the matter with their healthcare professional as a point of urgency. For minor clinical issues, the same procedure was planned however with less urgency. For non-clinical issues relating to safeguarding, social and/or legal issues, i.e. sharing medicines with children, there was a plan to

discuss the matter with the participant and inform them that due to the nature of the disclosure confidentiality must be breached and the social services and/or police will be contacted. However none of these instances occurred during the research.

In addition to clinical and non-clinical disclosures, participants might have felt the need to change the way they take their medication after the interview or focus group. Participants were repeatedly informed that the study was not a clinical review and should not impact on the way they take their medication. Additionally participants were reminded that the study should not impact on the way they take their medication before and after the interviews and focus groups. As described above, participants were given a support sheet with information signposting to areas of expertise about their medicines and how medicines should be taken. On reflection, there were no instances where this was a suspected concern.

### **Professional ethical standards and identity management**

The way in which the researcher presents him/herself to research participants has raised itself as a central ethical issue during this study and is not just concerned about how to get the most data but also about dealing with ethical commitments as a pharmacist. In this context there are two sets of ethical considerations to be followed, simultaneously. On the one hand, the customary social science qualitative researcher standards (or more formal British Sociological Association ethics standards) and on the other hand, the General Pharmaceutical Council Ethical Standards set out by the pharmacy regulatory body. The paper below was submitted to *Sociological Research Online* and accepted for publication in January 2016. This work was also presented at a John Snow College Seminar in 2015 and at the British Sociological Association's Medical Sociology Conference in 2014.

### **Transferring from clinical pharmacy practice to qualitative research: questioning identity, epistemology and ethical frameworks**

#### ***Abstract:***

Researcher identity can present methodological and practical, as well as epistemological and ethical tensions in sociological research. Identity management, such as the presentation of the self during a research interview, can have significant effects on the research encounter and data collected. An example of this is 'white coat syndrome', the disjointed interaction between clinicians and patients arising from unequal power and expertise, which can also occur in research encounters. For clinicians engaged in qualitative

social research, identity management can be particularly challenging given the potential for 'white coat syndrome'. Drawing on the experiences of a registered pharmacist undertaking qualitative research, we discuss the epistemological transition many clinicians go through when embarking on sociological research. We suggest that identity management is not just a matter of optimising data collection but also has ethical tensions. Drawing on Goffman's social role theory, we discuss the epistemic tensions between researchers' dual identities through positivist and constructivist frames, discussing the professional and legal implications, as well as the methodological practicalities of identity negotiation. We discuss conflicting professional and regulatory ethical frameworks, and ethics committees' negotiation of intervention and elicitation during research encounters and the conflict in managing professional, legal and clinical responsibilities whilst adhering to expected social research conventions.

### ***Introduction***

This paper is a reflection on the process of researchers crossing, and straddling, disciplinary boundaries and the challenges that this presents in terms of identity management and competing ethical obligations. It argues that the process of developing a sociological imagination presents challenges for those moving from a generally positivist discipline to conducting qualitative, social science research. This mobility requires a high degree of reflexivity, careful identity management and the negotiation of diverse, often competing, research design perspectives. This paper is structured to reflect the personal experiences of a pharmacist (APR) embarking on sociological research and frames the experience using Goffman's social role theory, that people present different identities in different social contexts. It describes the difficulty faced by pharmacists, and other clinical professionals, that embark on sociological research when deciding to present their clinical identities. The paper then considers the ethical tensions presented by dual identities and closes considering how different paradigmatic approaches attempt to deal with disciplinarily mobile practitioners.

We argue that clinicians, with traditionally positivist backgrounds, must negotiate conflicting epistemological, professional and ethical frameworks when conducting sociological research. We present here personal experiences and reflections of moving from the positivist disciplines and practices of medicinal chemistry and pharmacy into medical sociology. We suggest that such disciplinary mobility involves new epistemological engagement with the social world, which presents both opportunities and challenges for

those carrying out empirical research. On the one hand, this disciplinary mobility and epistemological fluidity offers the opportunity to engage with, and draw upon, a wider range of theoretical frameworks and methodological tools in addressing research questions. On the other hand, such mobility presents challenges; such as the effective bracketing of existing perspectives and developing a high level of trans-literacy. Moreover, we argue that such mobility can lead to what we might understand as ‘an identity crisis’ for disciplinarily mobile researchers. This identity crisis raises both practical and ethical questions. This paper, then, argues for a need for greater reflexivity in research design and ethical review to enable researchers to navigate identity management and conflicting ethico-legal obligations. To begin with, we offer some background context on the particular case we present here.

### ***Context***

This paper is a reflection on the challenges and tensions experienced by a pharmacist (APR – one of the authors) who trained and previously practiced in a predominantly positivist paradigm, and is now engaged in sociological qualitative research. Undertaking this sociological project necessitated a high degree of disciplinary mobility and led to the reflections offered here; firstly, we describe the project briefly.

### ***The Project***

Medicines adherence pertains to how a patient takes their medicine and if this is in accordance with the prescription – though many conflicting definitions exist. Healthcare disciplines (i.e. positivist disciplines) have provided answers to questions of patients’ medicines adherence but these have tended to be quantitative and so lacking the rich detail of qualitative data and have focused on demographic issues (e.g. age, ethnicity, gender) rather than taking into account the complex intersections of social life which might make people from certain groups less likely to adhere (e.g. women and caring roles)(Geertz, 1973). Moreover, despite attempts to provide a generalizable model and a definitive way to improve adherence, as is the aim of much of the research, the data to emerge from such studies has failed to reach a consensus (Nieuwlaat et al., 2014, Haynes et al., 2008). Some qualitative research has demonstrated that a more holistic approach that (a) samples a smaller number of patients, (b) looks to obtain rich, deep data and (c) locates the adherence question within the everyday lived experiences of patients as their lives pertain to factors, such as family life and diagnosis, rather than just their age, ethnicity, or gender might be more useful. Whyte et al. (2002) present a good alternative

to a positivist consideration of medicines in their work on the social lives of medicines. Here medicines are described 'beyond their material (chemical) properties' as objects which negotiate social meaning through different actors. Describing mothers' medication of children with coughs and colds, the authors state that medicines are used to send social messages; to the child that they care for them, to their husbands and neighbours that they are not negligent mothers and to themselves that they are good mothers. Insights such as this present something of a dichotomy within the ontology of medicines adherence; on the one positivist hand, therapeutic chemical entities used to prevent disease and on the other constructivist hand, a social tool used to negotiate relationships. Webster et al. (2002) expand on this in their discussion of lay pharmacology. Here medicines are understood and used through a lay paradigm of understanding in relation to efficacy, side effects and safety. This literature supports a qualitative approach to medicines adherence. As a result, we are undertaking a phenomenological project using interview and focus group methods to elicit data and draw on constructivist frameworks in theorizing patients' medicines use. The wider aim of the project is to inform interventions to facilitate 'better' medicines adherence – although, again, many definitions of 'better' adherence exist. Although the subject of the project (i.e. why patients are not adhering to their medicines regimen) is one highly familiar to positivist healthcare practitioners, a constructivist epistemological approach is not. As such, as a healthcare practitioner, negotiating an epistemological framing for the research - developing a 'sociological imagination' - was challenging and it is this process that we reflect on here.

### ***Developing a sociological imagination***

In the UK healthcare practitioners are largely educated within the positivist paradigm. Whilst medical sociology has been taught to medical and nursing students for a number of years, the majority of the curriculum tends to remain rooted in positivist, quantitative 'ways of doing' and natural science (Muller et al., 2014). Moreover, medical sociology has been adopted into the pharmacy curriculum to a much lesser extent. This paradigm, which underpins subsequent healthcare practice, encourages research that is repeatable, objective and positivist. As Timmermans and Berg (2003) show, the hierarchy of research and evidence in science and healthcare places a higher value on data which satisfies these criteria. Elsewhere, Vickers et al. (1997) have also noted that qualitative case-study research based on a small number of participants, which is limited in its generalizability, is considered inferior in healthcare. Phenomenological inquiry, and indeed qualitative research informed by constructivist approaches more generally, largely lacks the objectivity

and repeatability that is valued highly within a positivist framework. As a pharmacist, a science-based health profession, moving to a more constructivist discipline and, thus, 'changing gear' to align with the epistemological views of phenomenology was difficult, presenting challenges relating to identity management and ethics.

Educating health professionals within positivist frameworks might limit the extent to which they can be 'disciplinarily mobile' and limit inter- and cross- disciplinary work. If pharmacy, for example, were to work within a positivist tradition and social sciences to continue to be welded to highly critical constructivism, we risk reproducing the disciplinary silos that the interdisciplinary agenda works hard to move away from. This is not to say that we should work inter-disciplinarily (or engage with diverse epistemologies) just for the sake of it, but rather that there needs to be a real effort made to be disciplinarily flexible and mobile to address research questions in the most appropriate way.

Aligning the research subject with an appropriate epistemological paradigm provided an excellent way to shift long-held beliefs about qualitative and quantitative research and to begin developing a sociological imagination to address the research question. Such epistemological flexibility also provides the scope for practitioners to move away from healthcare research consistently undertaking large quantitative studies, and to think more critically about a wider variety of methodological approaches to particular research problems. Whilst healthcare education is teaching health professionals about research paradigms, professional practice often cultivates positivist perspectives with many judging the quality of research on the number of subjects in the study; the bigger, the better. APR's clinical experience as a pharmacist has been that less concern is put on what research is trying to find out but rather research findings and their applicability to patient care. A more holistic understanding of a wider variety of research methods and design was needed to address the research question of medicines adherence and would be useful for any healthcare professional entering research. Reading about the history and development of social research was essential, although at times the concepts seemed abstract, philosophical and difficult to relate to everyday practice, patients or pills. A key focus, then, became disentangling research and research findings from their immediate applicability to practice and examining the wider lifeworld in which patients' and professionals' beliefs and behaviours are formed and performed.

Although many healthcare professionals' educational background is peppered with psychology and sociology, they rarely stray from a positivist paradigm - although they may

wander into the realms of post-positivism on a liberal day. One truth, posited by an object and only revealed through the scientific method of experimentation, repetition and validation is how most healthcare practitioners are trained to understand the world and is ascribed the most value in practice. The concept that there is more than one theory of knowledge can be jarring. Exploring different paradigms in an attempt to understand reality, and the way things are (i.e. ontology) is an area that is very rarely discussed or considered once healthcare professionals leave education and get into practice. For APR, adopting a constructivist lens changed what he understood medicines to *be*. By accepting a framework of multiple-constructed truths, how could he be sure that the evidence supporting the supply of medicines was ‘true’? Without being able to rely on the familiar confidence intervals and statistics as markers of ‘truth’, supplying and recommending the use of potentially lethal pharmaceuticals, suddenly, became a lot more difficult.

Although healthcare professionals are under increased pressure, in a healthcare landscape characterized by increasing managerialism and target-driven working conditions (Hanlon, 2000), an engagement with different epistemological positions can dramatically alter the way research outcomes are understood and applied to practice. Discovering constructivism, the theory that meaning and knowledge are built through subjective conscious perceptions of objective characteristics, can result in a fundamental shift in epistemological and ontological beliefs. Ferguson, when discussing phenomenology, describes this shift as ‘not a new way of studying reality but the consciousness of a new reality’ (Ferguson, 2006: 25). Taking a constructivist approach, a capsule of paracetamol, for example, can be understood as more than its ‘objective’ properties - its colour, size, shape, and ingredients. Instead, a constructivist approach also includes the subjective understandings of what the capsule, and its properties, *mean* to patients - a remedy, a choking hazard, a hassle. Dingwall and Wilson (1995) echo this and discuss the way in which the tablet starts as a blank canvas for patients and is inscribed with social meanings by practitioners through discourse and interaction – in their case, pharmacists. As a pharmacist, ‘inscribing social meaning’ was not something APR had identified as part of his everyday work. That the social constructs of an object only exist when they are perceived through subjective consciousness and are valuable in understanding what a medicine is, presented an alternative approach to evidence-based practice. That these constructs can only be accessed through experiences, and so qualitative research, is a far cry from the familiar double-blind Randomised Control Trials (RCTs) characterised as the pinnacle of evidence-based practice. Acknowledging that systematic reviews are used as the ‘gold

standard' of science and medical knowledge in just *one* particular paradigm out of many, presented itself as something of a eureka moment.

### ***Epistemological flexibility***

For healthcare professionals, being flexible in the epistemological approach taken in research is challenging given that the majority of practice is focused on positivist understandings of the social world. Given this, the development of a sociological imagination, although difficult, may be ultimately beneficial for other healthcare practitioners embarking on sociological research. Based on APR's experience of such epistemological flexibility and disciplinary mobility, we examine ways in which the challenges of epistemological flexibility can be addressed by practitioners moving into, or looking to incorporate, a more constructivist framework in their research.

Returning to APR's own experience of disciplinary mobility, constant reflection and multiple modes of learning helped considerably. In particular, writing down what Wright-Mills calls 'fringe thoughts' helped unfamiliar notions and theoretical frameworks develop substance, which then snowballed into understanding; for example understanding the vocabulary of epistemology and how the different paradigms are presented. Looking up the definition and synonyms of words helped too, as did considering what the polar opposite would be for the theories trying to be grasped (Wright-Mills, 1954). Put briefly, phenomenology is founded on the process of bracketing off and *transcending* pre-existing prejudices and biases (Moustakas, 1994). Bracketing in phenomenology involves reflecting and removing any pre-existing or pre-conceived ideas about a phenomenon; setting aside judgments about the natural world to enable the essential structures of a phenomenon to be understood (Creswell 2007; Moustakas 1994). Taking a transcendental phenomenological approach and practicing 'bracketing' were also employed to develop a sociological gaze. Bracketing out or identifying preconceived understanding of a phenomenon, and rejecting these assumptions, enabled me to be reflexive in the analysis of data.

Some scholars argue that a true and complete sense of 'epoché', that is bracketing off previous beliefs and prejudices, cannot be achieved. However the practice may still be beneficial by identifying biases and 'opening up' to the idea of a different paradigm of knowledge. Discourse analysts and linguists may argue that one can never truly transcend all previous knowledge and prejudices about a given subject, if the same language is used to describe it (Moustakas, 1994). An example of this from the perspective of a clinician might be the word 'intention'. As a pharmacist the word intention might mean a 'plan',

perhaps pertaining to a patient's plan for discharge from hospital or pharmaceutical care but in the context of phenomenological research, intentionality refers to a fundamental process of experience. Intentionality is a corner stone of phenomenological research and refers to the 'focus of attention', describing the process where a consciousness *intends* towards an object (Crotty, 1998). Subjective processes of conscious perception (that is knowing, judging, remembering, desiring) are *intended* towards the objective characteristics of the object (that is its size, shape, colour). The resultant consciousness or experience is constructed from two sources; the subjective perception and the objective characteristics. Relating this back to the perspective of a positivist clinician, a single word can have very different meanings when it is employed in different epistemological frameworks. Being 'open' to a new paradigm of knowledge involved a degree of epistemological, and personal, ambiguity as the supposed certainty and superiority of RCTs and evidence-based medicine, which had characterised APR's education and practice up to that point, was sacrificed (or at least critiqued) in favour of constructivist framings. As Voltaire is often quoted, 'doubt is not a pleasant condition' (Buckingham et al., 2011: 146); and certainly transferring and doubting accepted frameworks of knowledge from clinical practice into social science research was further complicated through the negotiation of multiple identities.

### ***Identity management in research***

The gear change from a positivist way of understanding medicines adherence to a constructivist approach necessitated a critical examination of the researcher's own role within the project and its findings. If research is approached from a positivist perspective, researchers would be looking to gather objective findings, control for biases and remove themselves as much as possible from the research encounter to elicit an objective 'truth'. However, in developing a constructivist approach to the question, researchers must acknowledge that they will always influence the research, as they are part of the social world that they are researching. For APR this was difficult to accept as he had always practiced, like many clinicians, in an environment where care must be standardised, objective, and fair. Being disciplinarily mobile and moving into the social sciences from a heavily positivist background, we began to critically reflect on the role of the clinician in research.

This reflection on the clinicians' role in the research process is primarily centred on researcher identity and, in particular, the tensions between the two disciplines, and

subsequent identities, which are straddled by those undertaking social science research as practicing healthcare professionals. The social reality we inhabit is dynamic; discourse changes between our friends, our colleagues, our family and our healthcare professionals, as Goffman and others have described in their work on role theory (Berger, 1963). Familiarity with this phenomenon was established through comparison with a similar phenomenon seen in clinical encounters, often referred to as 'white coat syndrome'. This phenomenon describes the effect that a healthcare practitioner's perceived status can have on interaction and, indeed, the patient's physiological state in reality. The white coat phenomenon arguably stems from the disjointed interaction between patient and practitioner, arising from unequal power and expertise distribution (Dingwall and Pilnick, 2011). This unequal power dynamic can mirror that between participant and researcher. Within research, clinicians' identity as registered and practicing healthcare professionals is a key issue, in that data collection and rapport with participants may change fundamentally if participants are aware of the clinicians' professional role. Just as the identity of the clinician influences what a patient says and how they behave in clinic, participants can also be influenced by the researcher and adapt behaviours to meet the perceived expectations of the researcher. It is well documented that characteristics of the researcher may influence the research encounter (Savvakis and Tzanakis, 2004). A positivist position would attempt to limit this influence to ensure objectivity and validity and this was certainly APR's initial inclination during the research design process. However, the constructivist position is to accept this influence as a rich source of data and manage it openly (Ansdell and Pavlicevic, 2001). To refer back to our current study investigating patients' lived experiences of taking medicines as they are prescribed, the role of the researcher is critical in ensuring that the data captured is a representation of the everyday lived experiences of participants, rather than participants' attempts to satisfy the model of a 'good patient' to a pharmacist.

If participants are made aware that a social researcher is also a practicing healthcare practitioner (in this case a clinical pharmacist), there is a risk of a particular kind of front-stage performance (Goffman, 1959) in which participants take on the role of 'compliant' patients (Richards and Emslie, 2000). In doing so, the interaction itself may be renegotiated to become less of a research encounter and more of a clinical intervention. This presents a challenge in a wider context for researchers who are also practitioners, in deciding on their own presentation of self, their role within the research encounter and the social expectations and ethical demands of that role.

***Presentations of the self***

This paper now turns to discuss the practical and ethical implications of presenting the self as clinical and non-clinical, briefly describing the ethical conflict generated from dual-identities engendered through regulatory organisations and professional bodies that represent clinicians and researchers.

Goffman's seminal work on the presentation of the self in everyday life clearly provides a key theoretical point of departure (Goffman, 1959). He described the phenomenon whereby as humans our identities are fluid, contextual and dynamic. Presentations of the self include how we dress, how we speak, and our facial expressions, to name but a few, and represent the negotiations of expressions that *we give* (intentionally) and that *we give off* (unintentionally). Our expressions are in turn internalised by those around us, who, based on their previous exposures and assumptions, construct an impression of us. The impression, Goffman argued, is a manifestation of our perceived identities, on which, others can expect or elicit specific stereotypical behaviours or roles.

Richards and Emslie (2000) describe this in interview interactions. They compared what similar cohorts of participants said in interviews with a GP (Richards) and a sociologist (Emslie), noting that the identity of 'GP' overshadows the personal characteristics of the interviewer, suggesting that "who respondents *think* you are affects what you get told" (Richards, 2000: 75). Perceived identities and impressions then, inform the behaviours of those around us, dependent on their preconceived expectations of the identities we have expressed. The expressions that *we give* then, represent the identities that we wish to project to those around us. This could be wearing a stethoscope and white coat to express clinical professionalism. The expressions that *we give off* may be our body language or tone of voice, which might, equally, express clinical professionalism and feed into the expressions *we give off* unintentionally to those around us. In turn, those around us would identify us as clinical professionals and may alter the expressions *they give* to elicit responses and behaviours that they associate with the identity of a clinical professional (Goffman, 1959). As a pharmacist, this meant consideration of the expressions that APR *gives* or *gives off* and meant being aware of how he reacted or did not react to participants' disclosures about medicines use or misuse during interviews.

***Presenting the self as a pharmacist-researcher***

Presenting the self as a pharmacist has the potential to remove the distance from the participants' usual healthcare structures that a non-clinical researcher might have. In

presenting the self as a practitioner, participants may locate the researcher as an actor within 'the system'. Although many patient advocate groups increasingly focus on addressing the imbalance of power, knowledge and resulting communication barrier between healthcare professionals and patients, Dingwall and Pilnick (2011) have recently suggested that this imbalance of power persists. When researchers, then, present themselves as practitioners, there is a risk that this imbalance would translate to research encounters outside of the clinical space. This would change the context of the data collection process, potentially engendering more of a paternalistic relationship in which patients may feel accountable to the researchers as a representative of the healthcare system. Effectively this would negate the advantage of qualitative research as conducted by a social scientist that is not part of the healthcare system. If the researcher sits inside of the usual healthcare structures and professions, participants may more carefully manage their own identity to present themselves as a 'good patient'. Similarly, the context of the interaction may shift from research to clinical intervention.

Presenting the self as a practitioner also carries risks of inadvertently altering participants' behaviour after the research encounter. In this case, participants may feel the need to change the way they take their medication after the research as a result of their medicines use behaviours becoming problematised because they are the topic of study. In other words, because participants have been asked *by a practitioner* to discuss their medicines use, this may indicate to participants that there is something wrong, or at least worth studying, about their medicines use which may lead them to altering their behaviours. The risk that participants will change their medicine-taking behaviour due to influence from the research is potentially reduced if participants are unaware the researcher has a clinical background. There is an additional challenge for clinical researchers in maintaining this neutral presentation of self, which is not to slip into their role as a clinician and start to proffer healthcare intervention or advice. For a pharmacist, this may manifest itself as recognising prescription medicine misuse and giving the participant advice about how to use their prescription medicine. If participants are to be unaware the researcher has a clinical background, researchers should ensure their body language, facial expressions and tone-of-voice are consistently neutral in response to what the patient discloses in line with their given off non-clinical identity.

Palmeieri and Stern (2009) discuss the role of honesty in the professional-patient relationship, citing themes of shame and protection as justification for accepted untruths in

the clinical setting. A clear demonstration of presentation of self in everyday life occurs when patients present themselves by saying something that is not necessarily true to obtain services or medication or in this case, tell a pharmacist what they want to hear (Palmieri and Stern, 2009). Identifying the researcher as a part of the healthcare structure has implications on the nature of the data that is collected, arguably making it more about what participants think the researcher wants to hear, and patient-professional interaction.

***Presenting the self as a researcher only***

On the other hand, presenting the self as a non-clinical researcher, having distance between the researcher and the researched, could be justified as being important to optimise data collection and minimize researchers influencing participants' usual healthcare or service use. Presenting the self as a researcher-only has negative consequences in that clinicians lose their healthcare expert status and right to offer the participant advice about their medication. This initially does not seem like a significant loss, after all, the clinician is only 'giving up' this status during study encounters. Indeed considering methodological frameworks, philosophies and the actual method of conducting an interview, the Vancouver School of Doing Phenomenology stressed the importance of 'not losing awareness of context and self as a researcher' (Halldorsdottir, 2000). In this the school is advocating a demarcated awareness of the self as a researcher and the self as a clinician. The 'suppression' of the clinical identity, however, presents a conflict if a participant discloses a particular issue during a study encounter that the expert status of a clinician could help resolve. For example if a participant disclosed that they were taking two medicines which carry a high risk of drug-drug interaction and negative effects, as a clinician and pharmacist, it would be socially acceptable and appropriate to recommend withholding one of the medicines to avoid patient harm. In an encounter where the self is presented as a non-clinical researcher, would it be socially appropriate to alter the patient's pharmaceutical regimen? A researcher who is not also a clinician would not be expected, or might not have the necessary expertise, to offer prescription advice. Could clinicians presenting themselves as non-clinical researchers potentially be giving up an ability to reduce harm? In a situation when a patient discloses a danger to themselves through an inappropriate use of medicines, pharmacist or clinician status could be useful in preventing harm to the patient in a way which social researcher status may not. As well as being a practical and methodological dilemma, this also presents an ethical issue.

***A question of ethics***

Whilst Richards and Emslie (2000) show the presentation of self can impact data collection, ethical tensions can also prove problematic. In the context of a pharmacist conducting social science research, there are two sets of, often competing, ethical considerations to be followed simultaneously. On the one hand, the customary social science standards formalised in the British Sociological Association's Ethics Standards and on the other hand, the General Pharmaceutical Council Ethical Standards set out by the pharmacy regulatory body.

Clinicians conducting research will have expertise of, what they see as, poor healthcare behaviours and participants may disclose these during the research encounter. As a clinician there is an expectation that we will intervene to improve the participant's health behaviours, in the interest of the patient's wider healthcare outcome. This is mandated in the ethical standards of the regulatory body with the General Pharmaceutical Council (GPhC) Ethical Standard 1.7, stating that pharmacists should 'be satisfied that patients or their carers know how to use their medicines'. This obligation to intervene in medicines misuse directly contradicts the norms of social research in which focuses on understanding every day and normal behaviours even when those might be considered deviant or 'incorrect'.

Registered pharmacists are therefore statutorily obliged to work with patients until they are clinically satisfied that the patient knows how to use their medicine correctly. Such intervention, however, would shift the nature of the encounter from research to clinical involvement, from elicitation to intervention. The British Sociological Association's Ethical Statement 25 speaks of caution of participants forgetting they are being studied in relation to consent. If the interview is re-negotiated into a clinical intervention, rather than elicitation, we risk the patient forgetting they are being studied and breaching sociological ethical standards. Additional ethical frameworks and opinions, such as the professional pharmacy body the Royal Pharmaceutical Society, the NHS Research Ethics Committee and institutional level ethics committees, might add further contention.

***Avoiding contention in ethics committee negotiations***

Operating within these conflicting ethical and professional frameworks presented several problems – delaying the institutional ethics approval process. This is reminiscent of the NHS ethics process, and indeed ethics process in the US and Canada, in which social researchers are forced to fit the square peg of constructivist, qualitative research into the round hole of

positivist, quantitative clinical research (van Teijlingen, 2006, Murphy and Dingwall, 2007, Dingwall, 2008). Members of the ethics committee focused on APR's obligations to influence medicines use if he became aware of a medicines use issue. Disclosure of medicines use issues to pharmacists carries social, as well as professional and legal, expectations that medicines use issues would be resolved or referred to a general practitioner (GP). In clinical pharmacy practice, the relationship between the 'expert' pharmacist and their patient allows for medicines issues to be resolved directly through expert-novice advice-giving however in a research setting, a social or qualitative researcher may not have the necessary expertise to identify problems with prescribing or the necessary expert-novice power imbalance to give advice or to refer to a relevant authority. The social expectation there, then, is directed away from influencing the participant's usual healthcare and directed towards limiting the influence the research has on the participants' usual healthcare. However when the researcher has registrant status, healthcare expertise and professional obligations, researchers and members of the ethics committee must be able to negotiate a truce between identifying potentially risky behaviour patterns, which regulatory bodies would usually expect clinicians to directly address, and not influencing the participant's usual healthcare as per conventional sociological research.

### ***Final thoughts***

On reflection, many of the issues presented can be considered through positivist and constructivist perspectives. In a positivist gaze, a clinician will always be a clinician regardless of their environmental context or presented self and so would always have their regulatory and ethical responsibilities as a clinician. In a constructivist paradigm however, the clinician's identity is relative to the role within the encounter and the self that they present (Goffman, 1959). In a research encounter their identity, responsibility and expectations would then be as a non-clinical social science researcher, and this could be argued to negate any medico-legal obligations. There are clear epistemic, methodological and ethical tensions between the identities of researcher and clinician when attempting to conduct qualitative, social science research.

As highlighted by Banton (2005), social research is influenced by the researcher's personal traits and characteristics; with objectivity in the social sciences only achieved through interaction with other researchers. As Finlay (2002) suggests, clinical researchers could be encouraged 'to tell 'confessional tales' about dilemmas and decision-making in the research process'. Interacting with other researchers can be reflective in nature; drawing

on the experiences of different researchers. Consequently there could be a call for clinicians conducting qualitative research, to reflect and develop a discourse to use in the field, which incorporates both their identity as a clinician and their desire for brutally honest data. Equally a Bourdieuan analysis of inequality in cultural, or disciplinary, capital may be needed to address tensions between clinicians and social scientists, to deliver insights into this issue.

A functionalist analysis of ethical committees, institutions and frameworks may reveal that although manifestly these mechanisms aim to deliver safe and ethical research, latently they produce a sub-culture of clinical researchers who merely 'jump through the hoops' of bureaucracy without thinking ethically about their research. Regulatory bodies, such as the General Pharmaceutical Council and professional bodies such as the British Sociological Association, are in a position to open a dialogue to negotiate ethical practices of pharmacy registrants conducting sociological, qualitative research. The same is also true of other practitioners undertaking social science research who are potentially subject to similar epistemological and ethical dilemmas. Open dialogue between regulatory and professional bodies and, indeed, between researchers themselves might refocus the continued debate around research ethics in qualitative healthcare research.

### **Conclusion**

In conclusion, the identity of many clinicians will be first and foremost as a clinician, but the process of ethics approval, reflection, and review can lead to a realisation that first and foremost, we are just human beings. Developing a sociological gaze, moving away from the quantitative objectivity of a natural science-based health profession such as pharmacy into the realms of largely qualitative social research can be, and has been, a difficult transition and by no means can it be completed easily – if it ever can be completed. Our position, for the time being at least, is that clinicians are just as capable to give sociology a voice as anyone, *if* they can negotiate their position within the research encounter successfully.

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## Appendix D: List of publications associated with this thesis

This list includes published journal articles, published abstracts, oral conference and poster presentations that are associated with this work.

### Journal publications

**Rathbone A. P.**, Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) Systematic review and thematic analysis of patients' experiences of medicines adherence. *Research in Social and Administrative Pharmacy, in press*

**Rathbone, A. P.**, Mansoor, S. M., Krass, I., Hamrosi, K., & Aslani, P. (2016). Qualitative study to conceptualise a model of inter-professional collaboration between pharmacists and general practitioners to support patients' adherence to medication. *BMJ Open*, 6, 3.

**Rathbone, A. P.** & Jamie, K. (2016) Transferring from Clinical Pharmacy Practice to Qualitative Research: Questioning Identity, Epistemology and Ethical Frameworks. *Sociological Research Online*, 21, 4.

**Rathbone, A. P.** (2014) One down, seventy-four to go; there is a lot more to research than I thought there would be. *The Pharmaceutical Journal*, 293, 50.

### Published abstracts

**Rathbone A. P.**, Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) A phenomenological investigation of patients' lived experiences of medicines adherence in cardiovascular disease. *International Journal of Pharmacy Practice*, 24 (Suppl. 2) pp.23 doi: 10.1111/ijpp.12278

**Rathbone A. P.**, Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) A phenomenological investigation of patients' lived experiences of medicines adherence: men with diabetes in primary care. *International Journal of Pharmacy Practice*, 24 (Suppl. 1) pp. 21 doi: 10.1111/ijpp.12258

**Rathbone A. P.**, Todd, A., Jamie, K., & Husband, A. (2015) "I've never been a big tablet taker": a phenomenology of the experience of medicines adherence in men with diabetes. *Journal of Epidemiology and Community Health*, 69 (Suppl. 1 A75-A76) doi:10.1136/jech-2015-206256.150

**Conference papers**

**Rathbone A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) A phenomenological investigation of patients' lived experiences of medicines adherence in patients with cardiovascular disease. International Social Pharmacy Workshop 2016, University of Aberdeen, 18-22<sup>nd</sup> July 2016 [Oral Presentation]

**Rathbone A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) A phenomenological investigation of patients' lived experiences of medicines adherence: novel directions for future intervention development. Durham University Postgraduate Pharmacy Conference, Durham University, 1<sup>st</sup> July 2016 [Oral Presentation]

**Rathbone A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M. & Husband, A. (2016) A phenomenological investigation of patients' lived experiences of medicines adherence: men with diabetes in primary care. Health Services Research and Pharmacy Practice Conference 2016, University of Reading, 5<sup>th</sup>-8<sup>th</sup> April 2016 [Oral Presentation]

**Rathbone A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M., & Husband, A. (2015) Medicines adherence as a lived, socially-constructed phenomenon of survival: a phenomenological investigation in men with diabetes. British Sociological Association's Medical Sociology Conference 2015, University of York, 8-11<sup>th</sup> September 2015 [Oral Presentation]

**Rathbone, A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M., & Husband, A. (2015) A phenomenological investigation into patients' lived experiences of medicines adherence in men with diabetes. Society of Social Medicine 57<sup>th</sup> Annual Scientific Meeting, Trinity College, Dublin 1<sup>st</sup>-4<sup>th</sup> September 2015 [Poster]

**Rathbone, A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M., & Husband, A. (2015) A phenomenological investigation into patients' lived experiences of medicines adherence: teaching a phenomenon. A Day of Knowledge and Wisdom, John Snow and Stephenson College, 1<sup>st</sup> June 2015 [Oral Presentation]

**Rathbone, A. P.,** Todd, A., Jamie, K., Banks, L., Bonam, M., & Husband, A. (2015) A phenomenological investigation into patients' lived experiences of medicines adherence in men with diabetes. Wolfson Research Colloquium, Wolfson Research Institute for Health and Wellbeing, 15<sup>th</sup> April 2015 [Poster]

**Rathbone, A. P.** (2014) A phenomenological investigation into the patients' lived experience of adherence: is improving adherence ethical? Scholars' Supper Stephenson College, Durham University, 28<sup>th</sup> November 2014 [Oral Presentation]

**Rathbone, A. P.** (2014) A phenomenological investigation into the patients' lived experience of adherence: identity management and ethical frameworks. Snow Seminar Series, John Snow College, Durham University, 26<sup>th</sup> November 2014 [Oral Presentation]

**Rathbone, A. P., Todd, A., Jamie, K., & Husband, A.** (2014) When is a clinician not a clinician? When they are a qualitative social scientist, British Sociological Association's Medical Sociology Conference 2014, University of Birmingham, 11<sup>th</sup> September 2014 [Oral Presentation]

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