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# Towards a **Process View of Adherence**

by

# **Peter Michael Ward**

A thesis submitted in fulfilment of the requirements

for the degree of

Doctor of Philosophy in Service Systems

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## **Declaration**

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

The work presented (including data generated and data analysis) was carried out by the author.

**Abstract** 

Through a review of adherence literature and thirty qualitative interviews, a

theoretical view of the adherence process has been created which enables an

understanding of the process from initial awareness of need through to post-

consumption assessment. This view is proposed to answer the research

question, what is adherence from a process perspective?

It builds on Service-Dominant Logic to theorise the act of adherence for the first

time. In this it views adherence as a complex relationship of interacting service

(eco)systems. This takes the theoretical understanding of adherence beyond

existing theories and models and into the act of consumption itself, thus providing

theoretical visibility of the end-to-end process of adherence.

The literature review and qualitative research identified six factors of adherence

and three rules governing the adherence process. Perhaps surprisingly,

interviews found little difference in causes of non-adherence between developed

and developing worlds. A quantitative survey operationalised these adherence

factors and rules through the development of a quantitative process of adherence

derived from the qualitative process. However, due to survey limitations this

research provided no additional insights.

A new viewpoint on adherence is advanced. This considers adherence as a

single act and therefore as an individual opportunity to be adherent. This permits

a greater focus on the enablers and inhibitors of adherence at a point in time

rather than it being averaged over many acts in different situations.

It also includes a discussion of managerial implications, proposals for future

research, and thoughts on research limitations.

**Keywords:** 

Adherence; Service-Dominant Logic; Service Systems

Χ

### **List of Abbreviations**

A-C Access-Consciousness (a type of value)

ABC Ascertaining Barriers for Compliance (an adherence project)

AIDS Acquired Immunodeficiency Syndrome

ASA American Society on Aging

ASCPF American Society of Consultant Pharmacists

BMQ Beliefs about Medicines Questionnaire (a survey instrument)

CHBM Children's Health Belief Model

CMOTS Client Motivation for Therapy Scale (a survey instrument)

COM-B Capacity, Opportunity, Motivation – Behaviour

DAI Drug Attitude Inventory (a survey instrument)

F2F Face-to-face

FP Foundational Premise (fundamental to Service-Dominant

Logic)

HBM Health Belief Model

HIV Human Immunodeficiency Virus

MARS Medical Adherence Rating Scale (a survey instrument)

MASES Medication Adherence Self-Efficacy Scale (a survey

instrument)

MMAS Morisky Medication Adherence Scale (a survey instrument)

MUSE Medication Understanding and Use Self-Efficacy Scale (a

survey instrument)

NGO Non-Governmental Organisation

P-C Phenomenal-Consciousness (a type of value)

S-D Service-Dominant (a type of logic)

TPB Theory of Planned Behaviour

TRA Theory of Reasoned Action

WHO World Health Organisation



### 1 Introduction to this Thesis

### 1.1 Introduction

This is a thesis about adherence as a process. Through literature reviews and qualitative research it develops a theoretical view of the adherence process. It also takes a first step towards testing the process quantitatively. It creates this process because currently there is limited theorisation of the end-to-end process. This is considered by many to be inhibiting the understanding of how people are adherent in their many different environments.

The overarching research question is therefore, what is adherence from a process perspective?

This chapter is structured as follows. Firstly a consideration of the adherence process shows that it is not well-defined theoretically. It then explains why an improved understanding is potentially important. The scope of this thesis is presented and its contributions to knowledge described. Finally it lays out the structure for the rest of the thesis.

This is visualised in Figure 1.

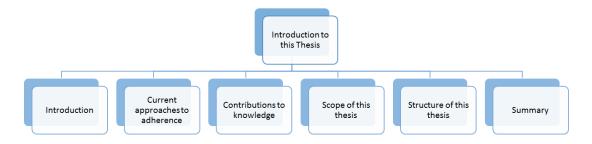


Figure 1: Chapter structure

# 1.2 Current approaches to adherence

Simplistically, adherence is consumption in accordance with instructions. This hides significant complexity in how adherence comes to be. Despite the use of behavioural theories in some papers, adherence is not well-defined theoretically. There are many practitioner-led operational definitions of the adherence process but these have a practical focus on issues inhibiting consumption or frequency of

consumption rather than providing a theoretical basis for why consumption may or may not occur.

These theories and definitions tend to be specific to their environments and they offer few proposals as to how they might be extended to apply more widely. Yet, the fact that adherence is researched in many areas of medicine suggests that it is of importance in a wide range of environments. It is to be hoped that a greater understanding of the adherence process will give new perspectives into what takes place when consumption happens and offer new insights into how it might be possible to modify patient approaches to consumption. Adherence therefore deserves greater and more widely applicable theorisation.

### 1.3 Contributions to knowledge

In his seminal report for the World Health Organisation (WHO), Sabaté (2003 p.xiii) said:

"[Increasing adherence] may have a far greater impact on the health of the population than any improvement in specific medical treatments".

This explains the purpose of this research. Medicine adherence is around 50% in the developed world and may be even lower in the developing world (ibid.). It is to be hoped that this research will enable those in the healthcare sector, from pharmaceutical manufacturers to staff at rural health facilities, to assist patients to be more adherent and therefore to achieve improved health outcomes.

As part of achieving these aims, this research has made several contributions to knowledge.

The main contribution to knowledge of this thesis is the creation of a qualitative process of adherence. This is a response to the overarching research question.

A second contribution is to consider a new understanding of adherence as an individual opportunity to be adherent rather than as an "average" of all consumption opportunities over a course of treatment. This perspective permits a closer focus on just what enables or hinders adherence at a point in time, when

as many as possible of the variables which influence adherence are as constant as possible. This approach is facilitated by the use of qualitative research which can engage with patients' lived lives.

Thirdly, it provides an enhanced understanding of adherence being the result of a complex relationship of service systems (Vargo & Lusch 2008; Akaka et al. 2013; Vargo et al. 2008), otherwise referred to (Wieland et al. 2012) as service ecosystems (Vargo et al. 2011), and involving an interaction of factors of adherence throughout the process from initial recognition of absence to final assessment of the value of having been adherent. This understanding goes beyond the existing theories used in adherence research and into the heart of consumption.

Fourthly, it has developed a quantitative process of adherence. This view could potentially inform quantitative research into adherence.

A fifth contribution is the diagrammatic description of the flow of Service-Dominant Logic (S-D Logic) (for example Vargo & Lusch 2004; Vargo & Lusch 2008; Akaka & Vargo 2015). As part of developing a theoretical view of the adherence process the diagram has also been augmented in two ways. Firstly by the application of the Integrative Framework of Value (Ng & Smith 2012). Secondly with a visualisation of service ecosystems (Vargo et al. 2011) which integrate the concept of the "multiple self" (Bahl & Milne 2010) as a means of understanding the competing priorities of ecosystem institutions. This diagrammatic representation of S-D Logic provides the basis for the qualitative process of adherence.

Sixthly, although the interviewees were not intended to be representative samples of their populations, the qualitative interviews suggested that reasons for non-adherence are broadly the same – although not necessarily for the same reasons – across developed and developing worlds. This surprising finding may have implications for future medicine formulations, since assumptions on agency and context may be causing adherence issues in the developed world in the same ways as for the developing world.

A less significant seventh contribution lies in an extension of the list of causes of medicine non-adherence over and above the list of 55 causes identified in an important report, "Adult Meducation" (ASA & ASCPF 2006).

### 1.4 Scope of this thesis

In order to permit development of a theoretical process of adherence, this thesis focuses on adherence as a theoretical construct.

Behavioural theories are sometimes invoked to understand adherence. Although behaviour can also be viewed as a form of adherence, it is out of scope except when such theories are analysed in the medicine consumption context.

The motivation of a patient to consume is within scope. A detailed analysis of how motivation arises is not in scope. The assumption is that motivation arises internally to the patient.

An analysis of context is included, but not how context as a whole comes to be.

Change of adherence over time is in scope, but only as it relates to the way a single occasion for adherence is affected.

### 1.5 Structure of this thesis

Chapter 1 is this introduction. Section A builds the case from theory and literature for moving towards a theoretical view of the adherence process and establishes the Qualitative Propositions. Section B builds the processes. It firstly describes the qualitative research which delivers the qualitative process, then moves on to derive a quantitative process and describe its initial quantitative exploration. Finally conclusions, limitations and suggestions for further research are presented. Appendices contain background information and data.

The structure of this thesis is shown diagrammatically in Figure 2.

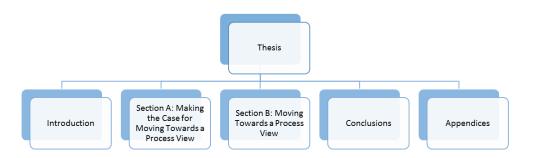


Figure 2: Thesis structure

# 1.6 Summary

This chapter has proposed the research question, what is adherence from a process perspective? It has laid out the purpose of the thesis and defined its scope. It has also proposed its contributions to knowledge, of which the qualitative theoretical process of adherence is chief. Finally, it has documented the structure of the rest of this thesis.

# **Section A: Making the Case for Moving Towards a Process View of Adherence**

### 2 Literature Review: Introduction

### 2.1 Section introduction

This section of the thesis makes the theoretical case for a process view of adherence. The first two chapters explore the concept of adherence, firstly outside of medicine consumption and then relating to medicine consumption. By doing this, it brings together factors of adherence which are then consolidated. Having done so, it evaluates the lens of Service-Dominant Logic to determine whether it can be used to structure the factors in a coherent way so as to form the basis of the theoretical process. The final chapter in Section A summarises the literature review and justifies the qualitative research which follows, establishing two Qualitative Propositions for investigation. By these means it makes the case for moving towards a theoretical process of adherence.

The structure of Section A is therefore as in Figure 3.

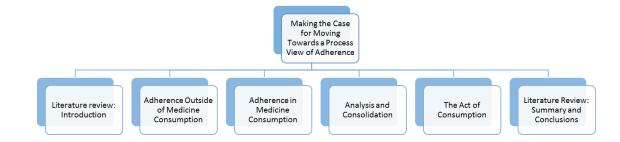


Figure 3: Structure of Section A

# 2.2 Chapter introduction

This chapter covers two main areas. The first considers the meanings of consumption before selecting the appropriate meaning for adherence. The second looks the current state of definitions of adherence. There is then a short consideration of how behavioural research can support the study of adherence.

The structure of this chapter is therefore as in Figure 4.

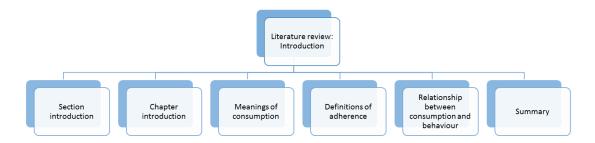


Figure 4: Chapter structure

### 2.3 Meanings of consumption

There are two views of consumption. Each one derives from its own definition of value: "value in use" and "value in exchange" (Smith 1776 p.30). The first relates value to that which is achieved by use — "...it is use that determines a thing's value..." (Marx 1959 p.51) — and the second to that which is achieved in exchange — "...money is the exact measure of the real exchangeable value of all commodities" (Smith 1776 p.39). Therefore, for those who consider that value occurs at the point of exchange, consumption refers to purchase. This is the more common usage, and where consumption theorisation has focused. Most theories of consumption of this type take an economic viewpoint, which has been described (Arnould 2007) as "a narrow one grounded in economics and psychology and dedicated to understanding and predicting purchase decisions".

However, for those who consider that value occurs at the point of use, consumption refers to use or experience. It is thought that use value was subordinated to exchange value as a result of the desire to measure national wealth and to facilitate international trade (Vargo & Lusch 2004). Since exchange value was easily measured as a form of national wealth while use value was not, exchange value predominated. Nevertheless, the two definitions of value continue in parallel and therefore there remain two definitions of consumption.

For the purposes of this work, consumption will refer to use and not purchase. The scope of this thesis and its viewpoint are therefore that adherence is related to use and not to purchase. There is no meaning in adherence to purchase, except inasmuch as the act of purchasing is a type of behaviour.

### 2.4 Definitions of adherence

The term "adherence" originates in the healthcare sector and so definitions of the word arise from there too. However, as will be demonstrated, there is no single agreed definition.

A simplistic concept of adherence is that patients take their medicine as and when they should.

The original term was "compliance", which originated in the 1950s as the importance of the concept was beginning to emerge. However, this is hardly used now because of the implied power relationship between prescriber and patient. Therefore, the definition has developed over time to reflect improved thinking on patient empowerment and wider perspectives. The 2012 Ascertaining Barriers for Compliance (ABC) project (ABC Project 2012; Vrijens et al. 2012) presented its view of the development of thinking around adherence over the last 35 years in table 2.1 of its report (reproduced as Table 1). In this table it can be seen that the relationship develops over time, with "compliance... with the clinical prescription" in 1976, moving to the more general terms "compliance... with medical or health advice" in 1979, then "agreed recommendations" in 2003, and eventually incorporating "patient participation [in the] agree[ment]" in 2005.

Table 1: Development in definitions of adherence (ABC Project 2012 p.22)

Definition	Authors - Year
Compliance is the extent to which the patient's behavior [in terms of taking medications, following diets or executing other lifestyle changes) coincides with the clinical prescription.	Sackett DL, Haynes BR; 1976
Compliance is the extent to which the patient's behavior coincides with the clinical prescription, regardless of how the latter was generated.	Sackett DL, Haynes BR; 1976
Compliance is the extent to which a person's behaviour [in terms of taking medication: following diets, or executing other lifestyle changes) coincides with medical or health advice.	Haynes R.B., Taylor D.W. and Sackett D.L.; 1979
Compliance is the extent to which an individual chooses behaviours that coincide with a clinical prescription, the regimen must be consensual, that is, achieved through negotiations between the health professional and the patient.	Dracup K.A., Meleis, A.I.; 1982
Adherence is the degree to which a patient follows the instructions, proscriptions, and prescriptions of his or her doctor.	Meichenbaum, D., Turk D.C.; 1987
Adherence is the extent to which a person's behavior - taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider.	World Health Organization; 2003
Adherence is the extent to which a patient participates in a treatment regimen after he or she agrees to that regimen.	Balkrishnan R.; 2005

This addition of patient participation to the definition of adherence attempts to address the issue of the instructions being imposed on the patient. However, the range of adherence definitions used both in theory and in practice do not fully reflect these enhancements. See examples in Table 2 (definitions used in papers with a practice focus) and Table 3 (from papers with a more theoretical focus). From these tables it is clear that both the more theoretical as well as the practice-based papers show *some* tendency to follow the development of thinking shown in Table 1, but that the penetration of more recent thinking is patchy in both theory and practice. Some of the definitions are so restrictive that it is unlikely that any patient could be deemed adherent, for example the idea (Sandy & Connor 2015)

that there are five ways that a patient could be non-adherent: "...altered their dose, forgotten to use the medication, stopped taking it for a while, decided to miss out on a dose, and taken less than instructed". On the other hand, some definitions tend in the opposite direction. One definition of non-adherence is a failure to collect medication for two months (Kripalani et al. 2007), while Gore-Langton et al. (2015) define adherence as patient self-reporting as having being adherent. This shows that there are multiple definitions of the term and little agreement as to which should be used (Becker 1985).

The problems caused by the range of definitions in Table 2 and Table 3 are stated by van Dulmen et al. (2007), who explain that the large variety of definitions complicates adherence assessments across multiple studies. It is also evident that varied definitions lead to different patients being considered adherent and therefore subject to interventions, and so affect measurement of outcomes.

Table 2: Sample definitions of adherence: practice-focused papers

Year	Definition	Reference
2002	"the extent to which a patient's behavior (in terms of taking medication, following a diet, modifying habits, or attending clinics) coincides with medical or health advice"	McDonald et al.
2007	"% of Prescribed pills taken >80% of prescribed pills taken [non-adherence is] failing to collect medications for 2 consecutive months"	Kripalani et al.
2015	"[non-adherence is] lack of correct behavior"	Tsega et al.
2015	"the extent to which patients follow the instructions given for prescribed medications"	Chew et al.
2015	"both compliance (proximity to treatment recommendation often simplified as the number of doses taken divided by the number of prescribed doses) and persistence (how long the medication is taken)"	Touskova et al.
2015	"self-reporting to have correctly taken the entire course of treatment"	Gore-Langton et al.
2015	"[non-adherence is] the extent to which [patients] have altered their dose, forgotten to use the medication, stopped taking it for a while, decided to miss out on a dose, and taken less than instructed adherence being defined as answering "never" to all five"	Sandy & Connor

Table 3: Sample definitions of adherence: theoretical and review papers

Year	Definition	Reference
2007	"the extent to which patients follow the instructions they are	Munro et al.
	given for prescribed treatments"	
2009	"the extent to which the patient's behaviour matches agreed	Nunes et al.
	recommendations from the prescriber"	
2011	"initiating the prescription, actual dosing in relation to the	Eliasson et al.
	prescription, and persisting with treatment"	
2012	"the extent of conformity to treatment recommendations with	Gadkari &
	respect to the timing, dosage, frequency, and duration of a	McHorney
	prescribed medication"	
2013	"the process by which patients take their medications as	Kardas et al.
	prescribed. Adherence has three components: initiation,	
	implementation, and discontinuation"	
2014	"correctly taking the full therapeutic course of treatment"	Bruxvoort et al.
2014	"those who reported to have taken the treatment as	Banek et al.
	recommended (in terms of timing and dosage) with no tablets	
	remaining"	
2015	"a ratio of the number of drug doses taken to the number of	Morrison et al.
	doses prescribed over a given time period"	

Definitions in these tables attempt to quantify adherence more comprehensively but a common one, for example used by Morrison et al. (2015), simply states that adherence is the ratio of medicine consumed to medicine prescribed. Because this is easy to measure it is often the one used in practical studies even though true adherence may be masked by this. For example, simple ways to falsify true adherence by this definition include taking more than the prescription to make up for gaps, taking the right dose of medication but at the wrong times, or simply disposing of the medicine.

van Dulmen et al.'s (2007) view of the problems relating to the diversity of definitions is repeated in many reviews of adherence research. One reason is that it prevents quantitative meta-studies. Because of this, the ABC Project 2012 (table 2.2 p.25) proposed a detailed definition for adherence (emphasis in original):

"The process by which patients take their medications as prescribed, composed of <u>initiation</u>, <u>implementation</u> and <u>discontinuation</u>.

"Initiation occurs when the patient takes the first dose of a prescribed medication.

"Discontinuation occurs when the patient stops taking the prescribed medication, for whatever reason(s).

"Implementation is the extent to which a patient's actual dosing corresponds to the prescribed dosing regimen, from initiation until the last dose.

"Persistence is the length of time between initiation and the last dose, which immediately precedes discontinuation".

In this definition "Implementation" is closest to the normal definition of adherence, while the additional terms provide extra detail in the practice of adherence. Some researchers after 2012 pick up on elements of this detailed definition. For example Kardas et al. (2013) use all terms except persistence, and Touskova et al. (2015) use persistence but then refer to implementation as compliance. However, most just ignore the additional terms. Since the measurement of adherence in its traditional sense is inconsistent, it is unlikely that this enlarged definition will prove easier to operationalise.

This study therefore aims to take a more theoretical perspective on adherence and the process of being adherent. This is not necessarily to replace operational definitions but to provide a greater understanding of the factors which may determine why adherence is achieved or non-adherence caused. It may be that this theoretical view of the process of adherence could support the development of more rigorous operational definitions.

# 2.5 Relationship between consumption and behaviour

It is necessary to consider why behavioural theories are sometimes called upon in theorisation of consumption. Warde (2005 note 6) explains that consumption

is simply a type of behaviour. Secondly, Arnould (2007) refers to consumption behaviour theory, thus linking consumption with behaviour. These ideas may demonstrate why, on occasions when the healthcare sector's thoughts on adherence are theorised, behavioural theories such as the Theory of Planned Behaviour (Ajzen 1985) and the COM-B model (Ripple 1955) are sometimes appealed to.

As a result, although behaviour outside of adherence is out of scope of this thesis, behavioural theories will be assessed for their support of consumption adherence when they are invoked.

### 2.6 Summary

The definition of consumption chosen for this work has been indicated as pertaining to use and not purchase. The many definitions of adherence have been considered, but as yet no definition has been derived for this study. It has been recognised that behavioural theories are sometimes incorporated into considerations of adherence.

# **3 Adherence Outside of Medicine Consumption**

### 3.1 Introduction

The purpose of this chapter is to explore the concept of adherence outside of medicine consumption. This is done in order to identify any contribution that such research might make towards the development of a theoretical view of the process of adherence. Research in this area is relatively limited compared to that of medicine consumption.

The structure of this chapter is as in Figure 5.

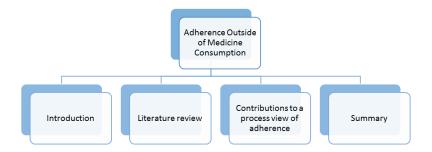


Figure 5: Chapter structure

### 3.2 Literature review

There is research into adherence outside of medicine consumption. Some of it relates to consumption, for example diet, smoking and drinking. Other papers mention behavioural adherence in a medical context; these are included here because of the limited amount of consumption-specific literature. These studies are localised in scope and make no attempt to theorise more widely than the empirical research from which it is derived.

McCullough & Willett (2006) investigated adherence to the Dietary Guidelines for Americans. They determined that higher adherence led to a longer period before succumbing to a major chronic disease. They did not theorise but simply reported their statistical study. There are many other similar studies which compare people's adherence to various diets and guidelines in relation to morbidity and mortality (for example Schröder et al. 2004; Guo et al. 2004; Fargnoli et al. 2008; Sofi et al. 2008). These, too, report rather than theorise. If adherence is defined

in such papers then measures relate to conformance to a dietary pattern or to achieving higher scores on an index.

There are some dietary adherence studies which go further. They generally indicate issues affecting adherence. St John et al. (2008) found an association between childhood obesity and a low level of family income. Povey et al. (2000) used the Theory of Planned Behaviour to identify a moderating link between perceived social support and healthy eating. Robinson et al. (2014) found that messages about social norms were more effective in achieving healthy eating than an injunction to eat healthily. Adherence was again not defined but can be assumed to be related to a level of intake of particular types of food.

A study in Nigeria on the use of mosquito nets for prevention of malaria (Russell et al. 2015) demonstrated that adherence to their use as bed nets was around three-quarters of the households possessing a net. The definition of adherence in this study was that a net was used the previous night. Discussion suggested that social support affects their use.

Several studies investigate actions against smoking. While most relate to antismoking medication there are some which focus on behaviour, either of the smoker or their support network.

One study in Netherlands (Segaar et al. 2007) looked at how nurses' behaviour affected smoking cessation on cardiac wards. In this study, adherence by nurses to an anti-smoking process was measured simply by whether they had implemented the process.

Another piece of research (Persky et al. 2005) explored smokers' adherence to a cessation program. This measured adherence through assessments by a counsellor of attendance at clinic and the smoker logging the extent of their smoking.

A descriptive study (Jacobs et al. 2014) considered adherence to the US Public Health Service's Clinical Practice Guidelines for Treating Tobacco Use and

Dependence of stop-smoking apps delivered on Facebook. There was no definition of adherence as such.

A further study (Terra et al. 2008) assessed whether attendance at Alcoholics Anonymous in Mexico was correlated with abstinence, adherence being measured by frequency of attending sessions. In all these studies there was no intention to theorise adherence as such, but simply to describe levels of adherence – as each one defined – to programs and practices.

### 3.3 Contributions to a process view of adherence

The main finding from this literature is that there was little assessment of causes of adherence or non-adherence, and therefore a lack of contributions to understanding the process of adherence. Where there was an indication it was mainly concerned with social pressure or support. If a theory was used in support of the research it was the Theory of Planned Behaviour.

## 3.4 Summary

This examination of adherence studies in the areas of non-medicine consumption and healthcare-related behaviour has shown that most have either very simple definitions of adherence or do not explicitly define it, thus failing to take a process view of adherence. There is no theorising in most of these papers but those that do either explore adherence using the Theory of Planned Behaviour or recognise the impact of social aspects. These two factors will be taken into account in moving towards a theoretical process of adherence in this research.

# **4 Adherence in Medicine Consumption**

### 4.1 Introduction

This chapter investigates the contribution of medicine consumption studies to creating a theoretical view of adherence. This is by far the most prolific area of adherence research. The relevant literature is reviewed below.

The structure of this chapter is as in Figure 6.

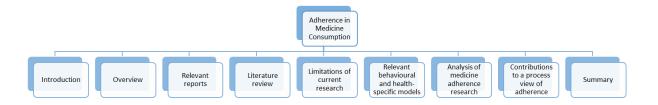


Figure 6: Chapter structure

### 4.2 Overview

Adherence to instructions for medicine consumption is a very basic requirement for health. Indeed, McColl-Kennedy et al. (2017) refer to it as "Comply[ing] with basics" yet non-adherence is a significant worldwide issue. For example, it has been estimated that 125,000 people die each year just in USA as a result of non-adherence (Burrell & Levy 1984); figures for other parts of the world are not known. In the developed world half of patients are not fully compliant with their prescription instructions (Sabaté 2003; Marcus 2013; Brown & Bussell 2011), and it is thought that the proportion of non-adherence is higher in the developing world (Sabaté 2003). Since adherence is so central to outcomes, it is unsurprising that the World Health Organisation has stated that improvement in adherence levels could be more important than improved medicine (Sabaté 2003 p.xiii), and that access to medication is necessary but not sufficient for successful treatment of disease. Therefore the opportunities for health improvements delivered through improved adherence could be significant.

## 4.3 Relevant reports

Much practical research has been done into the issue of adherence (Brown & Bussell 2011; Sabaté 2003). Sabaté's seminal World Health Organisation report is particularly germane. Peterson et al. (2003) found 95 studies on adherence. More recently, a review of reviews (van Dulmen et al. 2007) identified a total of 38 systematic literature reviews of adherence papers. A simple search (below) indicated that over 1200 (or more probably almost 19,000) medicine adherence papers have been published. The field of adherence research is therefore continuing to expand.

Sabaté's World Health Organisation report is a milestone in the field. Building on his work, another empirical report (ASA & ASCPF 2006) categorised 55 causes of non-adherence using the five "dimensions" of Sabaté's report. This was produced jointly by the American Society of Consultant Pharmacists and American Society on Aging and provides a useful summary of causes. More detail of each of these reports is considered here.

# 4.3.1 World Health Organisation report, 2003

Sabaté (2003) identified five interacting sets of causes inhibiting adherence which he categorised within five dimensions. These were causes arising from the patient's socioeconomic status, their relationship to the health system and to therapy, their own issues, and their condition (see Figure 7). There was no intent to perform a theoretical analysis of how these causes relate to each other. They are simply empirical. Sabaté's report has been cited over 4500 times.

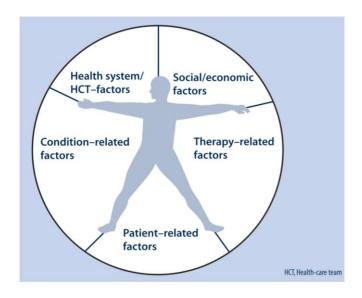


Figure 7: Five interacting dimensions of adherence (Sabaté 2003)

## 4.3.2 Adult Meducation, 2006

The report written by the American Society of Consultant Pharmacists and American Society on Aging (ASA & ASCPF 2006), "Adult Meducation", has perhaps the most practical list of issues affecting adherence that has been produced to date. It used the five dimensions propounded by Sabaté for WHO (Figure 7) to create a detailed table of 55 causes that can affect adherence (Table 4). While these 55 causes make a useful contribution, they have no underlying theoretical basis and are simply the result of observations. There is also some repetition and overlap in the list, such as "Medications with social stigma attached to use" and "Feeling stigmatized by the disease", "Medication cost" and "High drug costs, copayments, or both". However, despite these minor weaknesses it can provide a basis for assessing the validity of qualitative interviews. If the interviews only find a small subset of the list then it would imply a limited coverage of known causes. However since the scope of the list is limited to the USA it may be expected that additional causes can be uncovered in a set of interviews that include input from Western Europe and the developing world. In fact, one assumption was that causes of non-adherence in the developing world would be different to those in the developed world, but in interviews this was found not to the case.

Table 4: The 55 causes reported to affect adherence (ASA & ASCPF 2006)

1. SOCIAL AND ECONOMIC DIMENSION	4. THERAPY-RELATED DIMENSION
Limited English language proficiency Low health literacy Lack of family or social support network Unstable living conditions; homelessness Burdensome schedule Limited access to health care facilities Lack of health care insurance Inability or difficulty accessing pharmacy Medication cost Cultural and lay beliefs about illness and treatment Elder abuse  2. HEALTH CARE SYSTEM DIMENSION	Complexity of medication regimen (number of daily doses; number of concurrent medications)  Treatment requires mastery of certain techniques (injections, inhalers)  Duration of therapy  Frequent changes in medication regimen  Lack of immediate benefit of therapy  Medications with social stigma attached to use  Actual or perceived unpleasant side effects  Treatment interferes with lifestyle or requires significant behavioral changes
Provider-patient relationship	5. PATIENT-RELATED DIMENSION
Provider communication skills (contributing to lack of patient knowledge or understanding of the treatment regimen)	Physical Factors
Disparity between the health beliefs of the health care provider and those of the patient  Lack of positive reinforcement from the health care provider  Weak capacity of the system to educate patients and provide follow-up  Lack of knowledge on adherence and of effective interventions for improving it  Patient information materials written at too high literacy level Restricted formularies; changing medications covered on formularies  High drug costs, copayments, or both  Poor access or missed appointments  Long wait times	Visual impairment  Hearing impairment  Cognitive impairment  Impaired mobility or dexterity  Swallowing problems  Psychological/Behavioral Factors  Knowledge about disease  Perceived risk/susceptibility to disease  Understanding reason medication is needed  Expectations or attitudes toward treatment  Perceived benefit of treatment
Lack of continuity of care	Confidence in ability to follow treatment regimen
3. CONDITION-RELATED DIMENSION	Motivation
Chronic conditions  Lack of symptoms  Severity of symptoms  Depression  Psychotic disorders  Mental retardation/developmental disability	Fear of possible adverse effects Fear of dependence Feeling stigmatized by the disease Frustration with health care providers Psychosocial stress, anxiety, anger Alcohol or substance abuse

### 4.4 Literature review

## 4.4.1 Quantitative analysis of adherence papers

It is challenging to determine how many papers on medicine adherence have been written. Two types of search were performed: searching the MEDLINE database for papers in academic journals, and using Google Scholar. MEDLINE is the primary component of PubMed and contains over 23 million references to journal articles in the field of life sciences. The results of these searches, shown with Google search terms, are listed in Table 5.

Table 5: Results of searches for adherence papers

Search term	MEDLINE	Google Scholar
"medicine adherence"	18792	1220
+"medicine adherence" +theory	312	427
+"medicine adherence" +"self efficacy"	578	216
+"medicine adherence" +"grounded theory"	66	56
+"medicine adherence" +TPB	14	31
+"medicine adherence" +TRA	3	22
+"medicine adherence" +HBM	5	30
+"medicine adherence" +CHBM	1	0
+"medicine adherence" +"COM-B"	0	3

"self efficacy" (the term also finds "self-efficacy") relates to Bandura's Theory of Self-Efficacy (Bandura 1977; Bandura 1997; Bandura 1982). "TPB" is the Theory of Planned Behaviour; "TRA" is the Theory of Reasoned Action, "HBM" is the Health Belief Model, and "CHBM" is the Children's Health Belief Model. "COM-B" is a behavioural model for which the name is not an abbreviation. These theories and models are discussed later.

Although Google Scholar correctly shows that there are adherence studies making use of COM-B, the MEDLINE figures more accurately represent the importance of this field of research. Grounded Theory was included in the search since it is a method of analysis rather than a theory applied to the research; this allowed it to be excluded from the list of papers which apply a theory of behaviour to the research.

Since MEDLINE's figures are more realistic than those of Google Scholar, one reason for the disparity might be the wide variety of journals in which adherence research is published. While the journal Patient Preference and Adherence naturally has a large number of adherence papers, a sample of others includes the Bulletin of the World Health Organisation, AIDS Care, the Journal of Clinical Hypertension, Frontiers in Pharmacology, the Journal of the American Medical Association, BMC Health Services Research, the British Journal of Pharmacology, Medical Care, Quantitative Health Research, Drugs, the Journal of Clinical Pharmacy and Therapeutics, the Health Psychology Review, Patient Education and Counselling, New England Journal of Medicine, PloS One, Research in Social and Administrative Pharmacy, Transactions of the Royal Society of Tropical Medicine and Hygiene, the Malaria Journal, and by no means least the Journal of Service Research. The breadth of journals in which adherence research is published may inhibit Google Scholar from finding them all. It also means that there is no single high-ranking journal in which adherence research is published except perhaps the Journal of Service Research. Unsurprisingly, the journal which appears to have the highest focus is Patient Preference and Adherence, an online journal.

Therefore, taking MEDLINE's figures as accurate, they suggest that less than 2% of research references a behavioural theory. Even if those of Google Scholar were to be closer to being representative, around 45% of medicine adherence research references a behavioural theory. However, a review of the use of theory in medical research (Painter et al. 2008) indicated that almost 70% of research which referenced a theory was "influenced by theory" rather than using it. If this figure were to be applied to Google Scholar's figures in Table 5 then only 16% of medicine adherence research actually adopts a theory; if applied to MEDLINE's figures then the number is less than 1%.

## 4.4.2 Themes in adherence papers

Reviewing the relevant literature, it is possible to identify a number of themes. This assessment of themes makes good use of systematic literature reviews and so-called "reviews of reviews" in an aim to ensure best coverage of the literature.

The van Dulmen et al. (2007) review of reviews looked at 38 systematic reviews, identifying the interventions and successes referenced in each. The range of evaluated interventions was wide, but in many papers the processes followed were inconsistent and under-reported. One interesting comment in their paper was about the idea of repackaging tablets in dosage groups rather than individually. While this may be intuitively obvious as an intervention, they stated that no theoretical research had been conducted into whether this actually improved adherence. Their cautious perspective was justified by another literature review (Connor et al. 2004) which discovered that there is uncertainty about its effectiveness. While this review of reviews attempted to divine theoretical justifications for interventions, any which they did find were restricted to particular interventions rather than providing an overarching understanding of the adherence process. Perhaps due to the non-optimum methods that they saw in so many pieces of research, their review found that only 45% of interventions resulted in improved adherence, and only 33% in improved outcomes.

Another systematic review in the same year (Kripalani et al. 2007) looked at 38 papers describing randomised control trials. It too found significant heterogeneity between papers such that a pooled analysis was not possible. They called for additional research into which causes are most responsible for changes in adherence.

A systematic review by Haynes et al. (2008) found that there are "only a few relatively rigorous trials of adherence interventions", while those that do exist "provide little evidence" that adherence can be consistently improved without significant expenditure in clinical settings. Such bold statements do not give much hope for improvement without a change of approach aimed at gaining a deeper understanding of the real causes of adherence.

Kardas et al.'s (2013) review of reviews brought together a list of causes of non-adherence from 51 reviews. Its conclusion from this wide survey was that most so-called causes actually had uneven effects on adherence. This is true of many papers: causes of non-adherence are postulated and investigated but seen ultimately to have an inconclusive effect. Based on reviews and reviews of reviews it is tempting to believe that inconsistent methods, lack of theory, and failure to understand adherence at a qualitative level all have an impact on the identification of the true causes of non-adherence in people's ever-changing lived lives.

Continuing to move forwards in time, a systematic literature review (Fuangchan et al. 2014) of antimalarial drug adherence also created its own list of causes from the 16 papers it reviewed. However, as found in other reviews, a lack of underpinning theories and inconsistent approaches between papers meant that "immense disparity" was found in methods, reporting and conclusions.

Finally in this series of systematic reviews and reviews of reviews, a synthesis by Rathbone et al. (2016) of qualitative research identified themes relating to dislike of medicines, patient perceived need, medicine side effects, medicine cost, and medicine regimen. Echoing thoughts from earlier reviews, and giving credence to the importance of the overarching research question in this thesis, its authors opined that there is much still to be learned from qualitative research into what adherence actually "is".

Leaving aside systematic reviews, some themes are apparent when looking at individual papers. Firstly, there is a theme in the literature focused on patient motivation to adhere (Seiders et al. 2014; Kreps et al. 2011; Kok et al. 2012; Cornford & Lichtner 2014; Neiheisel et al. 2014; Firlik 2013). These generally assume that motivation is the key to increasing adherence.

As seen above, a second theme is papers which attempt to determine causes of non-adherence. These are empirical rather than employing a theoretical framework (Horne et al. 2005; Vermeire et al. 2001), and generally provide lists. Perhaps the most notable list is in the Adult Meducation report discussed above

(ASA & ASCPF 2006) with its list of 55 causes placed within a structure based on Sabaté's five dimensions (2003). Later papers tend to repeat the same causes in different ways (Jackson et al. 2010; Fischer et al. 2010; DiMatteo et al. 2007), but there appears to be a growing focus on how a patient's beliefs about medicine affect their adherence.

A third theme is medicine characteristics. Papers report problems such as tablet size or medicine taste, and relative preferences for one formulation over another (Stewart et al. 2016; Hill et al. 2007; Bhosle et al. 2009; Mennella et al. 2013). These characteristics relate to the medicine itself plus patients' interactions with it. However, this theme is very sparsely populated, the assumption being, as intimated above, that motivation overcomes negative characteristics.

A fourth is the focus on instructions. Since adherence must involve instructions this is not surprising, but research into this is not as extensive as might be expected. However, a significant earlier review by Horne et al. (2005) reported that patient recall of verbal instructions was less than 50% and that writing down the instructions helped with adherence. Another paper (Osterberg et al. 2005) reported on the importance of instructions being as simple as possible.

Fifthly, many papers consider patient characteristics. While it is suggested that personality traits are not good predictors of adherence, there is evidence that patient beliefs are important (McHorney & Gadkari 2010).

Sixth and finally in this list of themes, very many papers discuss the need for, or evaluation of, multiple forms of intervention to improve adherence rates. This is discussed in two reviews of reviews (Peterson et al. 2003; Kardas et al. 2013). Kardas et al. (2013) suggested in their review that "multifaceted interventions may be the most effective answer", but at the same time they found that many of the reviewed papers reported mixed or limited success (for example Ruppar et al. 2008; Demonceau et al. 2013; Rowe et al. 2007). It is nonetheless a potentially important seam of literature which will be thought about in greater detail later.

As can be inferred from the above, there are papers which recognise the need to think about dyads. However, these tend to be the dyad of patient and prescriber rather than, for example, patient and medicine or medicine and consumption environment. An in-depth review stated that no cause of non-adherence has been "consistently related" to adherence nor is "fully predictive" (Vermeire et al. 2001). They continued by saying that a cause of "the lack of progress" in adherence research is the absence of the "crucial factor: the patient's perspective". They also found no mention of theory in their "comprehensive review" covering 30 years of research.

### 4.5 Limitations of current research

There are three limitations with the practical research mentioned above. Firstly, most research has had a primarily Western focus and may not be completely applicable in the developing world. Secondly, there has been a concentration on age-related issues in USA and HIV/AIDS-related issues in sub-Saharan Africa. Thirdly, while the research may identify causes affecting adherence it generally does not analyse them theoretically or introduce any comprehensive theories to understand them. These are now considered in turn.

### 4.5.1 Western focus of research

The majority of adherence research focuses on the West, and most of that is performed in USA. A small sample of such research includes Ogedegbe et al. (2003), Sandy & Connor (2015), Haynes et al. (2008), Martin et al. (2012), DiMatteo (2004), and Kardas et al. (2013).

While any research into adherence is to be welcomed, a bias towards one region of the world may miss regional or even country-based differences in the causes of non-adherence. For example, the preference in one country for pills over injections may be inverted in another. Nevertheless it was discovered in this research that, despite finding such differences between countries in sub-Saharan Africa, causes of non-adherence were very similar. This suggests that

improvements in medicine formulations for the developing world could also benefit adherence in the developed world.

## 4.5.2 Developing world research

Most developing world adherence research has been HIV/AIDS-related. Of this, the majority has been in sub-Saharan Africa where AIDS is most prevalent (AVERT 2015). HIV/AIDS research has been performed in Botswana (Bisson et al. 2008), Ethiopia (Tsega et al. 2015), Nigeria (Adewuya et al. 2010), South Africa (Dahab et al. 2008), Tanzania (Roura et al. 2009), Uganda (Weiser et al. 2010), Zambia (Murray et al. 2009), and Zimbabwe (Skovdal et al. 2011). This HIV/AIDS focus is not surprising since leading NGOs are working to address HIV/AIDS and treatment must continue throughout the patient's life in order to be effective, thus motivating pharmaceutical manufacturers.

However, there is more general adherence research in Africa such as by Kok et al. (2012) and Munro et al. (2007). Other examples in sub-Saharan Africa include Tuberculosis – often associated with HIV/AIDS – in South Africa (Atkins et al. 2010) and Tanzania (van den Boogaard et al. 2012), and also hypertension in South Africa (Cassimjee & Suleman 2009).

This research has been of practical rather than theoretical intent. It is therefore likely that further important information on causes of non-adherence, including details which may be specific to particular medicines or be geographically localised, still remains to be captured. Although in general the causes of non-adherence in both developed and developing worlds were found to be similar it is accepted, for example, (Reynolds 2013) that developing world patients may have different wants and needs in terms of medicine taste, texture or package size.

### 4.5.3 Lack of theoretical consideration

As was discussed above, there is generally a lack of theoretical grounding seen within what is largely practice-based empirical research. Behavioural scientists and other researchers have proposed some theories to explain non-adherence,

but these do not seem to resonate with the needs of practitioners if the counts of such papers above are reasonable estimates.

However, there are some exceptions. The main theory used in adherence research is Self-Efficacy Theory. Some researchers have looked to the Theory of Planned Behaviour (for example Wu & Liu 2016; Al-Swidi et al. 2014). Other researchers have reached out to Ripple's (1955) COM-B model (including Eliasson et al. 2011). A few adherence researchers also endorse health-specific models. The most commonly used theories and models are described next in order to understand their contributions and limitations.

# 4.6 Relevant behavioural and health-specific models

The following models are sometimes invoked by adherence researchers, though often to provide guidance rather than actually being used. Therefore they are described in this section in order to understand their potential contributions to the development of a theoretical view of the adherence process.

# 4.6.1 Theory of Self-Efficacy

The Theory of Self-Efficacy was propounded by Bandura in 1977. He defined "self-efficacy as one's belief in one's ability to succeed in specific situations or accomplish a task" (ibid.). He considered that behaviour could be explained by a person's "expectations of personal efficacy [which] are derived from... performance accomplishments, vicarious experience, verbal persuasion, and psychological states" (ibid.). Diagrammatically, he viewed behavioural expectations as per Figure 8 which is reproduced as-is from his 1977 paper. This shows that, in his view, expectations of efficacy should be distinguished from expectations of outcome.

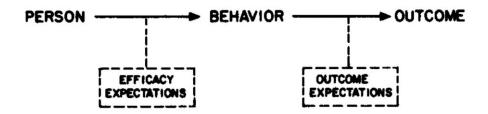


Figure 8: Bandura's Theory of Self-Efficacy (Bandura 1977)

From the figure it is possible to identify this theory as being based on what has become known as the "expectancy-value" family of models (Atkinson & Reitman 1956; Eccles et al. 1983). That is, a person's performance in a task can be explained by their expectation of the level of success – their perceived self-efficacy – combined with the expected value to them of the task (Wigfield & Eccles 2000). This implies that someone who has a task that can be performed easily and which has significant value to them will be more motivated to perform it than if they consider it to be difficult and/or of low value.

As seen below, this theory is subsumed into the Theory of Planned Behaviour and therefore requires no further consideration.

## 4.6.2 Theory of Reasoned Action

The Theory of Reasoned Action, often abbreviated as TRA, was developed by Fishbein & Ajzen in 1975. The two authors developed a model which showed how beliefs, attitudes and intentions could be understood to predict behaviour. This model was illustrated in the book which launched the theory and is reproduced as-is in Figure 9. As with Self-Efficacy Theory, it is an expectancy-value theory.

This model was eventually recognised as having several limitations. Its main assumption is that intention must lead directly to behaviour. A drawback is that a person's perception of success and value may not ultimately be accurate. Over time this simple model had to be modified to take account of wider issues not originally considered but which were found to arise in empirical research. Ajzen himself therefore superceded it with the Theory of Planned Behaviour.

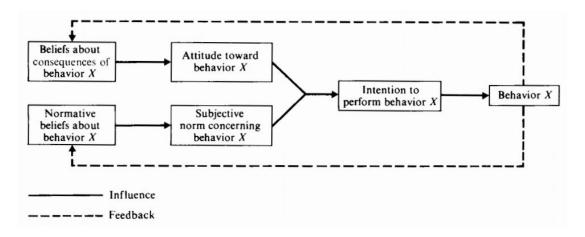


Figure 9: Theory of Reasoned Action (Fishbein & Ajzen 1975)

# 4.6.3 Theory of Planned Behaviour

In 1991 Ajzen (1991) took a look back at his Theory of Planned Behaviour (TPB) that he had propounded in 1985 (Ajzen 1985) as a follow-on to the Theory of Reasoned Action. The theory was illustrated in the 1991 paper and is portrayed as he created it in Figure 10.

He stated that the key enhancement of this theory over the earlier Theory of Reasoned Action was the incorporation of the person's perception that they had behavioural control over their actions. In his 1991 review, Ajzen stated that this addition to the Theory of Planned Behaviour was required because one of its limitations was that it did not recognise personal freedom to act. He went on to explain that inhibitors to action included time, money, skills and social support, and that these vary by time and place. In this enhancement he incorporated elements of the person's resources and their environment. He also continued to accept that the theory measured intentions rather than action.

The theory includes certain elements of behaviour which are relevant to a process of adherence. These are the person's attitudes or beliefs, subjective norms which include perception of social support, and behavioural control which is a part of perceived self-efficacy.

While there have been calls to "retire" the Theory of Planned Behaviour (Sniehotta et al. 2014), others either wish to extend it in various ways to make it

more fit for purpose (Armitage 2015; Conner 2015) or have already done so (Didarloo et al. 2012). The latter was done specifically for adherence research, adding a formal measurement of perceived self-efficacy to the theory although it could be argued that it is simply part of perceived behavoural control. As such, Bandura's Self-Efficacy theory is subsumed into the Theory of Planned Behaviour.

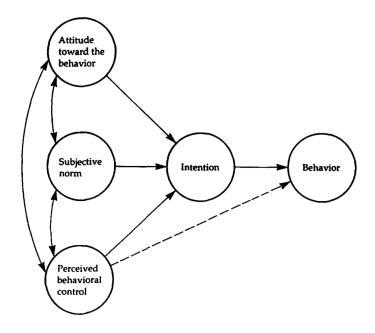


Figure 10: Theory of Planned Behaviour (Ajzen 1991)

As with the Theory of Reasoned Action, the limitation of this theory is that it reaches only as far as the intention to act. There is an implicit assumption that intention leads directly to behaviour but this link is not theoretically justified. By omitting such justification for this assumption it overlooks the significant possibility that it is not always true. This must also be considered for the theoretical process of adherence.

### 4.6.4 Health Belief Model (HBM)

The first health-specific model to be reviewed is the Health Belief Model (HBM). This originated as a theory relating to the use of preventive health services in the 1950s before being applied to adherence (Janz & Becker 1984; Rosenstock 1974). This is claimed as a major organising framework for understanding

adherence. However, it is a typical expectancy-value model in that it is based on two variables, the value of a person's goal and an estimation of whether any particular action will help with achieving it. In the health context, these two variables translate into the importance to the patient of getting well and the patient's expectation as to whether a health action such as taking medicine will contribute to their improvement.

The model mentions three patient beliefs, which later became four dimensions (Rosenstock 1974 p.330): personal susceptibility to a disease, disease severity, benefit of action and perceived barriers to action. As mentioned, these all relate to beliefs and expectations so the actual value eventually achieved not explored.

Janz & Becker's paper, a systematic review of 46 studies of the HBM, also mentions that a stimulus is necessary to trigger the decision-making process (Janz & Becker 1984). In addition it stated that research on this has been very limited. The authors emphasise that HBM is a psychosocial model that relates to attitudes and beliefs, therefore does not reach as far as the act of consumption. This is repeated in a book critiquing the model (Rapoff 2010). Janz & Becker suggest that some health behaviours are habitual or undertaken for non-health reasons, and recognise that there are some circumstances where health behaviours may be prevented by external issues such as medicine cost and issues which exist within the patient's medicine consumption environment.

This model, while including the patient's motivations and some elements of environment, does not fully consider either the patient or the environment and does not investigate the attributes of the medicine at all. Becker (1985) says that the most powerful dimension is the one relating to barriers, and within that dimension the main concerns are social approval and the lack of self-efficacy.

## 4.6.5 Children's Health Belief Model (CHBM)

The second health-specific model is linked with the first. The Children's Health Belief Model (CHBM) (Bush & Iannotti 1990) is based on HBM and integrates other behavioural theories: Social Learning Theory, Cognitive Development

Theory and Behavioural Intention Theory. It includes the four dimensions of HBM but considers that there are other causes which contribute to overall adherence, including the child's level of autonomy and the influence of the child's parent/guardian.

As with HBM, this is an expectancy-value model. It introduces two moderators in the form of autonomy and parental influence, the first of which relates to perceived personal freedom to act and the second another manifestation of social support. At the time of Rapoff's (2010) book, only one study had actually used the model fully, and in that study medicine consumption itself was not measured.

#### 4.6.6 COM-B model of behaviour

"COM-B" refers to the four elements of this simple model: (1) Capacity, (2) Opportunity, and (3) Motivation, combining together to produce (4) Behaviour. See Figure 11 for a diagrammatic representation of the model. This has been derived from the description of the theory in Ripple's 1955 paper, which does not include a diagram of the model. The focus of her paper was on behaviour of Social Services clients in relation to the services being provided to them by their caseworker.

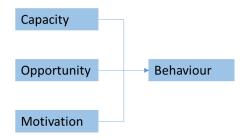


Figure 11: COM-B model after Ripple (1955)

Ripple noted in her paper that the main components had already been recognised earlier. The three drivers of behaviour were originally specified in an earlier book (Towle 1954 p.86). However it was Ripple who recognised their importance, operationalised the model, and brought them together in the format of Figure 11.

Each of the three input factors was defined in detail in Ripple's (1955) paper. Capacity related to a person's capability to act; Opportunity looked at self-efficacy and support within the environment; Motivation focused on the trigger of discomfort and perceived self-efficacy. This recognises the importance of self-efficacy and social support once again. However, as with other models there is an assumption that readiness for action leads directly to it.

## 4.7 Analysis of medicine adherence research

The empirical research creates some useful groupings of causes of non-adherence but does not try to generate any theoretical basis for them. Rather than focus on theory, practitioners tend to use existing practical definitions of adherence or create their own definitions as the basis of their work.

As we have seen, the main theories – the Self-Efficacy Theory, the Theory of Reasoned Action, the Theory of Planned Behaviour, the Health Belief Model and the Children's Health Belief Model – are used by practitioners, though not as widely as might be expected. The COM-B model is rarely used. The theories are typical expectancy-value models with a particular focus on value as relating to *a priori* expectations, and so they relate strongly to expectancy rather than the final realisation of value. It is necessary to go beyond them in order to gain a wider perspective of adherence, one that does not stop at the point of intention and that explains a greater proportion of what affects adherence.

Therefore it seems reasonable to suggest that medicine adherence remains under-theorised. It is mainly a practitioner-led field as a result of efforts to address mainly age-related non-adherence in North America and to improve HIV/AIDS treatment in sub-Saharan Africa. Non-adherence in most conceptualisations is primarily blamed on insufficient patient motivation (for example Hill et al. 2007; Munro et al. 2007; Svarstad et al. 1999; Seiders et al. 2014; Holmes et al. 2016). It is therefore clear that there is scope for moving towards a theoretical view of the process of adherence, since improvements could lead to significant health benefits for large numbers of people.

## 4.8 Contributions to a process view of adherence

From this literature review of medicine adherence there emerge several contributions to a process view of adherence. Perhaps the clearest contribution is that research which uses expectancy-value theories finds that self-efficacy and social support are major determinants of adherence. Considering themes, motivation is thought to be important, as are medicine characteristics and patient characteristics, particularly beliefs. Clear and appropriate instructions are also determinants of adherence. Other papers highlight the importance of subjective norms, the importance of the patient-doctor relationship, and the patient's ability to act coupled with potential inhibitors of action. It must be remembered that the theories focus only on the intention to act, which is no guarantee of action especially when external inhibitors are considered.

# 4.9 Summary

This survey of the literature of medicine adherence has highlighted the lack of theory in most research. However, it has indicated the use of or reference to some theories in a minority of papers. Such theories have limited coverage of the initial stages of adherence and do not extend to consumption. Because there is no theoretical basis for most practical research, there is much disagreement on theories which might be used and a lack of consistent application of theories where they are used or referenced.

# 5 Analysis and Consolidation

## 5.1 Introduction

This chapter analyses the literature reviewed in earlier chapters to identify themes. It then brings them together into three constructs under the headings of patient, medicine and environment. These themes are then expanded and defined under those three headings, and three reasons for consumption introduced.

The structure of this chapter is therefore as in Figure 12.

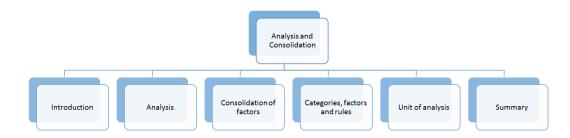


Figure 12: Chapter structure

# 5.2 Analysis

From the analysis of non-medicine consumption these points were seen in the literature. (1) There was little assessment of determinants of adherence or non-adherence. (2) Where there were indications of causes they were mainly concerned with social pressure or support. (3) If theory was used in support of the research it was generally Self-Efficacy Theory or the Theory of Planned Behaviour.

From the analysis of medicine consumption these points were seen in the literature. (1) Self-efficacy and social support are major determinants of adherence. (2) Motivation is thought to be important. (3) Medicine characteristics affect adherence, (4) Patient characteristics affect adherence, particularly beliefs. (5) Clear and appropriate instructions are also determinants of adherence. (6) Norms are important for adherence. (7) The patient's ability to act along with potential inhibitors of action are important to consider. (8) The relationship

between patient and healthcare provider can be important to adherence. (9) If a theory was used in support of the research it is usually Self-Efficacy Theory, the Theory of Planned Behaviour or the older Theory of Reasoned Action.

There is overlap in these two lists. It is therefore possible to combine them into rationalised list of eight components. The following elements have been found to be important in adherence. (1) Social pressure or support. (2) Self-efficacy. (3) Motivation. (4) Medicine characteristics. (5) Quality of instructions. (6) Patient's ability to act. (7) Inhibitors of action. (8) Patient-doctor interaction.

Although the above three theories are most often used to support empirical research, they are only expectancy-value theories and so any validity for actual consumption depends on the patient understanding their potential future. They have no direct link with action; they stop at the point of intention to be adherent and so cannot take the act of consumption into account. However, intention is no guarantee of action especially when external inhibitors are present at the point of consumption. This is a weakness in all expectancy-value theories, and means that there is no overall theoretical process of adherence that supports an understanding from prescription to consumption. It is necessary to go beyond these theories if a holistic process of adherence is to be created.

## 5.3 Consolidation of factors

It is possible to consolidate these factors. Analysing the list, there appear to be three main categories: the patient, the medicine and the environment. For the purposes of adherence, the patient can be defined by their motivation, their self-efficacy (or ability to act), and their beliefs about themselves and the medicine. The medicine can be thought of as its characteristics and the instructions. The environment can be considered to consist of the support or lack of support from social care or pressure – which in this research is assumed to include the relationship with the healthcare provider – and the inhibitors or enablers of action.

It will be useful to look in turn at each of these categories and the factors identified as being part of them.

## 5.4 Categories, factors and rules

### 5.4.1 Patient

For the purposes of this research, a patient is someone who consumes medicine. Patients may take their medicine for a number of reasons. Since a patient is a consumer in this sense it is reasonable to invoke wider consumption literature. Motivation, the ability to act and beliefs are also explored.

Two important questions are what consumers do and why they do it. Many authors define consumption as the integration of resources to create value for the consumer (for example Siltaloppi & Vargo 2014; Hibbert et al. 2012; Peters 2014). Resource integration is the process by which the consumer uses their capabilities in order to use the consumable with the purpose of creating value in use. These capabilities align with the patient's ability to act, their beliefs, and their motivation. Patients bring these to adherence as resources in order to create value in use from the medicine.

The environment should provide other resources in support of the patient's intention to be adherent. The process of resource integration, if consumption is to take place, requires that sufficient of the right resources are brought together. This is described as there being sufficient resource "density" for value in use to be achieved (Michel et al. 2007; Normann & Ramírez 1993).

For example, taking medicine may require a tumbler and some water. These are provided by the environment occupied by the patient. If these resources are not available then the patient may not be able to be adherent on that occasion.

Motivation has been identified as an important factor in why patients are adherent. At a basic level, Bhaskar (1993) stated that "absence" is the root cause of consumption. In the case of medicine consumption that absence relates to the patient's lack of health. This absence may also be the required "stimulus" to action (Janz & Becker 1984). The process of "absenting of absence [is] manifest in the satisfaction of desire" (Bhaskar 1993 p.43). Mingers (2011) identifies this process as a "feedback system... always trying to close the gap (absent an

absence) between the desired state of the system and the actual state of the system".

While the term "desire" is a potentially emotive word, for Bhaskar it had no moral overtones. Similarly, Ilmonen (2011 p.57) simply equates desire with a "specific need" for an "object". That object in this context is the medicine. He speaks of "needs and wants" (ibid. p.45), discussing how "the condition of need" becomes "a specific need, i.e. want" (ibid. p.48) through "identification [with] its object" (ibid. p.49). There is therefore a four-step progression. (1) Absence (of health). (2) This awakens a need (for a medicine). (3) This leads to the three equivalent ideas of desire, want or specific need (for a particular medicine). (4) Finally this results in "absent[ing] the absence" (of health) through obtaining and consuming the medicine, thus closing the loop in the system and restoring health.

A level of motivation – perhaps an increasing level – is required to move from one step to the next in this four-step progression. However, a lack of movement through these steps does not imply that motivation is not present. It is fundamental to Bhaskar's philosophy of Critical Realism (Bhaskar 2008 p.36) that "countervailing causes" may cause "generative mechanisms" such as motivation, which "endure even when not acting", to remain "unrealized" in practice (ibid. p.xxxi). This therefore recognises that the patient may not consume even when motivated if there are forces acting which prevent it. In our example this may be that a tumbler or water is not available, thus preventing the patient from moving from desire for health to the health expected as a result of the consumption of medicine. This is a potentially important consideration when considered against expectancy-value theories which assume readiness for action always leads to action.

However, there may be more to why patients take their medicine than just the fulfilment of their wish to regain health. Joy & Li (2012) observe that consumption decisions are "complex, often riddled with ambivalence, internal contradictions and even pathology". This observation is potentially explained by the Dialogical Self Model (Bahl & Milne 2010). This proposes that a person's internal dialogues

demonstrate the existence of "multiple narratives reflecting multiple selves" which represent "multiple realities". They go on to say that consumption is viewed differently by each self, while a "meta-self maintains a more balanced perspective... as a synthesizing activity" overall.

Perhaps the Dialogical Self Model does help to explain Joy & Li's conclusions. It certainly indicates that there are potentially multiple purposes to consumption and that they may be in conflict. Three consumption purposes, or goals, have been defined (Barbopoulos & Johansson 2016) as gain (functional, utilitarian), hedonic and normative.

In overview, the utilitarian goal takes the rational, objective, functional utility-maximising viewpoint. This is the one assumed to be operating in adherence decisions.

The hedonic goal relates to emotions, either positive or negative, and was identified by Hirschman & Holbrook (1982) as a result of empirical research. In adherence this may be relevant if, for example, consumption is performed in the presence of an otherwise-absent loved one or in a hospital with unpleasant connotations. Hirschman & Holbrook (1982) make three propositions regarding hedonic consumption. (1) "In some instances, emotional desire dominates utilitarian motives in the choice of products". (2) "[C]onsumers imbue a product with a subjective meaning that supplements the concrete attributes it possesses". (3) "[H]edonic consumption is tied to imaginative constructions of reality". These propositions suggest that rational adherence decisions can be overruled by influences such as the emotions aroused by a medicine, the intangible attributes of a medicine, and internal views of reality which may not match objective reality. Point three is especially relevant when considering expectancy-value theories.

Though hinted at originally in the Theory of Planned Behaviour, the normative goal was added to the first two by Barbopoulos & Johansson (2016) and is applicable to the consumer abiding by external restrictions. In the case of adherence this may be pertinent to the patient's support being present or otherwise, and their wish to engage with support from the appropriate source. It

may be also that the patient discovers that support varies depending on the environment in which they find themselves or perceive themselves to be. In addition, it is argued that the patient's perceived or actual environment will determine the nature of the norms they abide by.

Finally in this consideration is the importance of patient beliefs. Earlier analysis has indicated that these are seen to be of significant importance. Interestingly, in the conclusion to his paper on the Theory of Planned Behaviour Ajzen (1991) opined:

"...there is plenty of evidence for significant relations between behavioral beliefs and attitudes toward the behavior, between normative beliefs and subjective norms, and between control beliefs and perceptions of behavioral control".

In this analysis he is referring to beliefs, norms and external controls. It may be more sensitive in this context to rename "controls" to "instructions". Some might also at times rename "beliefs" to "values", for example in the list provided by Hibbert et al. (2012) of "values, norms, and required patterns of behavior", but the intent is the same.

#### **5.4.2 Environment**

Within this research, the environment is the situation in which the patient consumes the medicine. It is the combination of all of the aspects of the particular consumption situation which contribute to or detract from consuming the medicine in order to achieve value in use.

Returning to the earlier example, the tumbler and the water are part of the patient's environment. These are enablers of consumption.

Also as indicated above, another element of the environment is the support provided – or otherwise – by others. This includes the patient-doctor relationship. This viewpoint has been considered in the light of the Dialogical Self Model and is positioned here as being dependent on which environment the patient is in or

perceives that they are in. The norm rule, discussed above, relates directly to the environment.

This environment is usefully visualised by Easton (2010), who links it with the Critical Realist "contingent relationship". This refers to relationships which are "neither necessary nor impossible" to exist. This outlook implicitly recognises that the environment can vary since the relationships between elements of the environment do not necessarily obtain over time. There are many variables, which may include the time of day, the location, the availability of required contextual elements, and even the patient's capabilities at that time. This perspective suggests that even with all those specified elements place in the value creation environment the patient may still not take their medicine. This could be due, perhaps, to a lack of capability or a suddenly reduced desire, and shows how the patient must contribute their capabilities in order for them to create value. In this it is possible to see "contextual variety" (Ng & Briscoe 2012), which affects the patient's ability to realise value in use.

### 5.4.3 Medicine

At its simplest, a consumable is something which can be consumed. In these thoughts the consumable is the medicine. The medicine provides its resources into the consumption environment, where its resources are combined with the patient's resources to create value in use. The medicine's attributes may contribute to the patient being adherent or may detract from it. Features detracting from adherence may be, for example, that it is bitter or too large to swallow, or its formulation – tablet, injectable, etc – may be unacceptable to the patient.

The medicine's instructions are another contribution of the medicine into the consumption environment. Without accurate and accurately remembered instructions it is likely that adherence will not occur.

### 5.4.4 Beliefs, norms and instructions

From the foregoing, and referencing Ajzen (1991), it is possible to see that there in fact three "rules" which contribute to determining whether adherence will be achieved by the patient: beliefs, norms and instructions. It is reasonable to assume that these are always operating concurrently in any particular consumption context, and that they may either be aligned or in conflict.

## 5.5 Unit of analysis

Mainstream adherence research continues to define adherence as complying with instructions over the course of treatment. This means that it overlooks the fact that adherence to a course of treatment involves multiple separate opportunities to adhere to the instructions.

As may have become apparent in the analysis above, there is another way to conceptualise adherence. That is, that overall adherence is made up of a series of individual opportunities to consume. The circumstances each time may be different and should therefore be considered separately rather than as a homogenous whole as is currently the case. Each opportunity ultimately reveals its own decision and level of success.

Therefore, the unit of analysis in this research now turns to each opportunity to be adherent rather than considering adherence as an amorphous whole. In this way it can investigate causes of adherence and non-adherence as individual events. The whole is then the sum of each event, such that the total of the events over time then becomes the mainstream view of adherence. The aim of taking this approach is to enable analysis of causes of adherence and non-adherence at a point in time in order to understand the particular consumption situation at a time when all the many variables are as constant as possible. This is in contrast to taking what might be called averages of non-adherence reasons, especially in quantitative research which does so over many patients. It is clear from research to date that this averaging approach is unable to form a clear and consistent explanation of adherence within an overarching view of the process.

Taking this approach puts emphasis not only on the intention to be adherent at that point in time, but equally on whether consumption actually takes place. Behavioural models as used in adherence research are not able to do this. As a result of this omission, this literature review has not so far been able to investigate this important aspect of adherence. This research therefore needs a way of theorising actual consumption at a point in time. It explores this topic in the next chapter, evaluating a way of understanding consumption at the point at which it takes place: the lens of Service-Dominant Logic.

## **5.6 Summary**

This chapter has analysed the adherence factors arising from the literature review and grouped them into categories. These were seen to be the patient, the medicine and the consumption environment. A review of the factors in their groups was then performed, and consumption rules identified – beliefs, norms and instructions – arising from Hirschman & Holbrook (1982), Barbopoulos & Johansson (2016) and Ajzen (1991). It then took the position that in order to understand adherence more accurately it needs to be looked at as a series of individual opportunities to be adherent rather than consider it as an average of consumption over time. Finally, it raised the subject of the moment of consumption as a development of existing theories which stop at the intention to consume.

# **6 The Act of Consumption**

### 6.1 Introduction

Since mainstream behavioural theory has been shown to terminate its relevance at the point of the decision, this chapter evaluates the lens of Service-Dominant (S-D) Logic as a way of understanding the actual act of consumption. This may extend, or with the additions to S-D Logic discussed later potentially replace, the expectancy-value theories considered so far. This is because, by design, they can only explain the consumption process up to the point of the decision and it is necessary to go beyond these to get a more holistic perspective of the adherence process. S-D Logic is evaluated at this point since it focuses on consumption and may therefore provide new insights into adherence. This supports the unit of analysis since S-D Logic implicitly focuses on a single consumption event.

The structure of this chapter is as Figure 13.

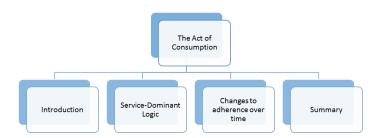


Figure 13: Chapter structure

# 6.2 Service-Dominant Logic

#### 6.2.1 Overview

As discussed previously, there are two competing ideas of value. The mainstream view of value is that value is embedded in goods during manufacture and distribution. Customers acquire that value at the point of purchase – value in exchange (Smith 1776). Smith's other view of value – value in use – is the one underpinning this research. It is here that S-D Logic concentrates. In the original paper launching S-D Logic written by Vargo & Lusch (2004), the value in exchange viewpoint was referred to as "Goods-Dominant Logic" to distinguish it

from their new (or in their opinion the original) perspective. This is, that value is assessed at the point at which consumption takes place. The basis of S-D Logic is embodied in 11 "Foundational Premises" (Vargo & Lusch 2008; Lusch & Vargo 2014; Vargo & Lusch 2015). The list can be found in Appendix A.

S-D Logic research states that "Service" in S-D Logic is not the same as "services" which are often mentioned in contradistinction to goods. S-D Logic's Service is considered to subsume both goods and services (firstly in Vargo & Lusch 2004).

As discussed earlier, the process of creating value in use requires the provision of resources from the patient, the medicine and the environment. S-D Logic refers to the value thus created as "value-in-context" because the value in use is created in the consumption environment, or context. Because value-in-context is created by the patient from this combination of their own and the medicine's resources plus the resources within the context, the value creation process is referred to as "resource integration" (Vargo & Lusch 2008). This recognises that the consumer must synchronise the use of resources in order to create value. As seen in earlier discussions, the patient's resources are their ability to act, their motivation and their beliefs, while the resources of the medicine are its attributes and its instructions.

S-D Logic claims that, because value-in-context cannot be delivered by medicine suppliers in isolation but has to be created by the patient using their resources, suppliers can only offer "value propositions" to patients (for example Lusch et al. 2014). These are provided to patients in the form of medicines or "offerings" (Ng & Smith 2012). It is the patient who determines the value of a medicine as they perform "value cocreation" (firstly in Vargo & Lusch 2004). This implies that each patient may cocreate more, less or different value from the same medicine because of the differing resources of the patient and the context and their differing responses to the resources of the medicine.

Because both patient and medicine supplier contribute to the value that is cocreated, S-D Logic refers to both consumers and suppliers as "actors"

(Giddens 1984; Vargo & Lusch 2011) to indicate their equality in the value cocreation process. At this time "patient" and "supplier" will be maintained to aid clarity but their equality is recognised and accepted. The term "context" will however be used from this point since it is a term which S-D Logic uses as an equivalent to "environment" used so far.

S-D Logic states that in the process of generating value-in-context the patient's primary resource is their "agency", which is defined as their skills and competencies, or in the terms of the discussion above, their ability to act. These skills and competencies are referred to as "operant resources". This distinguishes them from the "operand resources" which are resources which need action to be taken on them, such as medicine. The patient's operant resources interact with what the value proposition provides, which are "affordances" manifest as resources (Ng & Smith 2012). The patient's agency (operant resources) and the resources provided by the value proposition's affordances are integrated by the patient in context to cocreate value (ibid.; Vargo & Lusch 2006 p.283).

In all this can be seen a triad of patient, medicine and context. Exactly how they interact to cocreate value is not yet seen. Therefore to begin to illuminate this it is necessary to position them within the framework of S-D Logic. This requires firstly that S-D Logic be visualised.

## **6.2.2 Visualising S-D Logic diagrammatically**

The proposition of this section is that the parts of S-D Logic come together as depicted in Figure 14 below. Some of the points above will be repeated here for ease of reading. Later, this visualisation will be extended in support of achieving a more detailed perspective of the act of consumption.

The basis of cocreation of value is that the patient integrates resources from the supplier, the context and themselves (Vargo & Akaka 2009). The patient's resources are their skills and competencies (within which can be seen beliefs and motivation), otherwise referred to as agency, which may be enabled or restrained by the consumption context (Ng & Smith 2012). Resource integration only

happens in context. The value created is context-dependent (Flint et al. 2014), and is determined in use.

Resources need to be recognised as such before they can become part of the value cocreation process. Until they are so recognised they remain as "*potential resources*" (Peters 2014). Potential resources provided by suppliers are referred to in S-D Logic as affordances, and affordances become resources when acted on (consumed) in context. Their source is the supplier's offering, or in other words the value proposition of the medicine (Ng & Smith 2012).

Value-in-context is therefore cocreated by the patient in context using the resources provided by the medicine supplier's value proposition plus resources from other providers. As per Ng & Smith (2012), those resources are delivered as affordances – potential resources – by the offering, otherwise referred to as the value proposition.

In summary, the supplier's value proposition offers affordances which become resources in the consumption context. Further resources arise from other value propositions which exist in the consumption context. The patient brings skills and competencies to apply their agency on the resources, performing value cocreation activities to produce value-in-context. This is visualised as Figure 14.

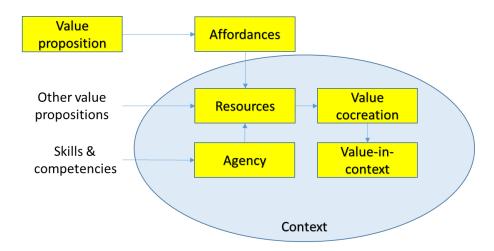


Figure 14: Service-Dominant Logic diagrammatically

This figure provides us with several useful insights. Firstly and obviously is the importance of context to the cocreation of value-in-context. Secondly, agency acts in context on resources but the affordances of the medicine are independent of context because they are not necessarily recognised as resources until the consumption context becomes apparent. Thirdly, other value propositions also provide resources in context, and the patient integrates these resources with the resources of the medicine's affordances arising from its value proposition to create sufficient density to achieve value-in-context through the process of value cocreation. The interaction of these multiple service systems (Vargo & Lusch 2008), including the patient, the medicine provider, the providers of other resources, and elements of context, is needed if adherence is to be achieved.

Reconsidering the example of the patient consuming medicine using a tumbler and water, the medicine is the value proposition of the supplier and provides its resources into the context of medicine consumption. Also in context are the tumbler and the water, provided by other suppliers as value propositions. The patient's agency – the resources they provide into the context – allows them to put water into the tumbler, put the medicine into their mouth, and drink the water so as to swallow the medicine. If there were to be a problem in the consumption context, for example a tumbler was not available, then another water container may be sought. A cup, which had not been noticed before, might be spotted and brought into the consumption context to hold water. The cup's affordance as a means to hold the water to swallow the medicine was always present out of context, but had never before been required for this use and brought into context.

## 6.2.3 Assessing S-D Logic against the requirements

The patient, the medicine and, importantly, the consumption context are recognisable in – and recognised by – S-D Logic. This therefore permits it to extend the expectancy-value theories discussed earlier which terminated before the point of consumption.

S-D Logic provides greater understanding of the fact that adherence can only be achieved when the operand resources of medicine are available in the

consumption context along with those of other value propositions, so as to permit the value cocreation process of adherence to proceed. It also confirms that the patient's agency must be sufficient for them to provide suitable operant resources in order for them to be adherent. It is this complex interaction of service systems which both highlights and also explains the challenges of understanding adherence, and therefore the need for a theoretical process view of adherence.

However, there are three points which still need clarification. Firstly, in common with the previously investigated behavioural theories, S-D Logic does not explicitly recognise the possibility of consumption not taking place. That is, it does not recognise non-adherence. It is already visible from the foregoing that there are potentially many reasons for non-adherence embodied in the patient, the medicine and the context, but a more formal assessment would be worthwhile in moving towards a process view of adherence.

Secondly, it is obvious that adherence is intended to provide value. However, it is necessary to consider when and what value is cocreated, and how it is assessed.

Third and lastly, there is a need to think about the three "rules". The instructions have been proposed to be one of the medicine's affordances. The patient's beliefs have been positioned as contributing to the patient's agency. But the norm rule has not yet been accurately located. It may be that the concept of service ecosystems will contribute to greater understanding.

The next two sections investigate these points. Firstly the norm rule, followed by non-adherence and assessing value cocreation.

# **6.2.4 S-D Logic service ecosystems**

One thing which may help clarify the relationship of the rules to context is a consideration of a relatively recent S-D Logic development, service ecosystems and their associated institutions (Akaka & Vargo 2015; Vargo et al. 2011; Greer et al. 2016). This concept refers to (Lusch & Vargo 2014 p.161):

"...relatively self-contained, self-adjusting system[s] of resourceintegrating actors connected by shared institutional arrangements and mutual value creation through service exchange".

This definition is a refinement of that used for the concept of the service system, and the two terms can be used interchangeably (Wieland et al. 2012). However, "service system" focuses more on connection of systems through value propositions (Vargo et al. 2008) while "service ecosystem", as seen above, is more to do with the systems in which the patient resides. Therefore, while recognising their essential equivalence, in this discussion the terms will continue to be used in the senses as here presented.

These systems are flexible, loosely coupled, and may be temporary. A patient can be in several service ecosystems at the same time (Greer et al. 2016) and service ecosystems may be nested (Vargo & Lusch 2015). Each service ecosystem has its own institutional arrangements, or "rules of the game" (ibid.).

To progress this concept it is useful to visualise what a combination of service ecosystems might look like in the patient's consumption context. An idea of one potential combination out of very many possibilities is shown in Figure 15. The service ecosystem labelled "Supplier of value proposition" represents the ecosystem which defines the institutional arrangements – including the rule of instructions – for consuming the medicine. If the patient is fully aligned with only that service ecosystem then it is to be expected, all things being equal, that they will be fully adherent. However, the patient is likely to be at least partially aligned with other ecosystems, and these may turn out to be different ones at each adherence opportunity.

Service ecosystems are therefore important elements of the consumption context and help shape the value cocreation process. However they are not the total context since this includes potentially many items required for the value cocreation process such as the previously considered tumbler and water. Nevertheless, the fact that a patient can be in many service ecosystems simultaneously may explain three things from previous discussions.

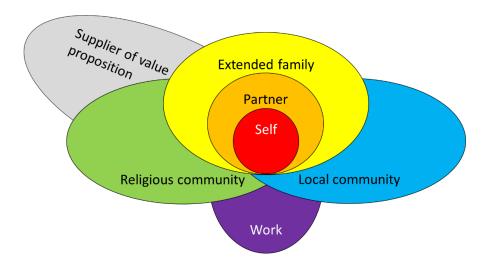


Figure 15: Possible service ecosystems represented diagrammatically

The first is the "multiple self" (Bahl & Milne 2010). A patient's decision-making will vary depending on which of the service ecosystems and their institutional arrangements they have in focus. It may be that each ecosystem is equivalent to a "self" in Bahl & Milne's theory. The observation that consumption decisions are "complex, often riddled with ambivalence, internal contradictions and even pathology" (Joy & Li 2012) can be understood by reference to service ecosystems as a result. What is perceived to be good in one service ecosystem may not be in another, hence the reported "ambivalence" and "contradictions". The concept of service ecosystems may therefore help to explain the "multiple self".

The second is the rule of norms. Each service ecosystem's "rules of the game" provide the norms that the patient must take into account or benefit from depending on the level of relatedness they feel to any particular ecosystem (de Brabander & Martens 2014). Decision-making will depend on which service ecosystem takes precedence. Therefore it is likely that the norms rule relates to one or more of the service ecosystems in which the patient exists or perceives themselves to exist. Which set of norms takes precedence will depend on the ecosystem which gains most attention in the adherence decision.

Based on this, it may be possible to see in these service ecosystems the origins of the varying levels of support which a patient believes they are receiving at any point. It may be that an alignment with one ecosystem will bring – or be perceived

to bring – support, while alignment to another will prevent that support from being present or being perceived as being there. This may be a very practical thing: if the patient shuns one service ecosystem in favour of another then the support from the first may be withdrawn for that particular opportunity for adherence.

The third relates to hedonic value cocreation. Here Consumer Culture Theory can contribute. This theory recognises that there are "differences in consumer emotional and imaginal response to products [which] appear closely tied to a variety of subcultural differences" (Hirschman & Holbrook 1982). Membership of the different, potentially competing, subcultures may be represented by occupying various service ecosystems.

Therefore, the patient may take into account their own beliefs, the norms of one or more service ecosystems, and the instructions of the supplier's service ecosystem when coming to a decision on whether or not to be adherent. If they do not follow the instructions of the medicine supplier then they may not cocreate the value-in-context that was intended, but that is a decision for the patient. It is for them to decide whether the results are satisfactory or not, since it is always the patient who assesses that value. This may be associated with changes to adherence over time.

### 6.2.5 S-D Logic value cocreation assessment

It can be assumed that the patient seeks to cocreate value-in-context. Therefore they need to understand in advance what value might be created and then determine afterwards what value was actually created. While they may recognise that the value cocreation process delivers value-in-context, if the medicine is effective then there should be longer-lasting value which remains after being adherent and which is probably more important than the value that was created in context.

One way of explaining the way in which patients assess value both in advance of and following consumption is the Integrative Framework of Value (Ng & Smith 2012). This framework was built on the foundation of S-D Logic. It proposes a

model whereby patients can assess what they perceive to be of value to them in the process of being adherent. It defines two types of value.

The first type of value is "Phenomenal-Consciousness value" (P-C value). This is equivalent to the value cocreated in context. It is referred to as "...the raw experience of creating value (goodness) in interactions around the experience... the phenomenon of lived experience... the actual engagement and use experience of the offerings". This may link to Hirschman & Holbrook's (1982) proposal that "...hedonic responses may be viewed as the essence of the usage experience", since P-C value is experienced rather than assessed.

The value that is assessed rather than experienced is the second type of value, "Access-Consciousness value" (A-C value). The term refers to the way that value is assessed outside of context, either in advance of consumption or in retrospect. This is described as "...the perception, introspection and memory (or imagination) of P-[C] value before (ex ante) and after (ex post)... the perception of goodness that drives choice ex ante and valuation ex post" (emphasis in original).

Their depiction of their model is shown in Figure 16. As can be seen, Ng & Smith reference the elements of S-D Logic using the epithet of "facets".

Ng & Smith (2012) identify a "paradox" at the heart of their model. That is, that P-C value is the value created by the patient at the moment of value cocreation, yet it can never truly be assessed since as soon as the A-C value assessment activity commences the patient must exit from the "raw experience of creating value", even if only momentarily.

This implies that value is cocreated at the P-C level for as long as the act of consumption continues. For some medicines the "act" may therefore incorporate not just the moment of consumption but its effects. For example, consuming medicine may happen in a moment but its effects may not become apparent for minutes or hours. Ideally, only when the patient can assess both the moment and the effect – the entire episode – can a complete *ex post* A-C value be captured

for the adherence event. However, an interim *ex post* assessment can be made at any time, implying that the judgement on A-C value may change over time.

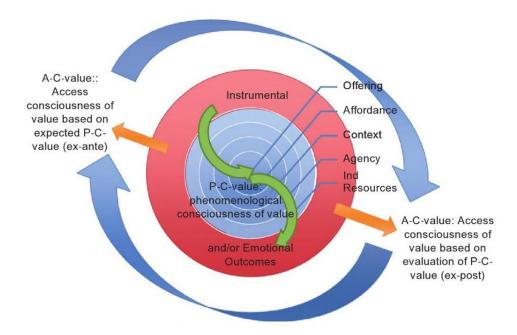


Figure 16: Integrative Framework of Value (Ng & Smith 2012)

A-C Value ex ante is all about perception of what will happen during value cocreation. This appears to mirror expectancy-value theories; until the moment of consumption all is perception and expectation. A-C value assessments can commence even before the medicine is obtained. However, ex ante assessments of value cocreation can only ever be perceptions of what might happen rather than the certainty of what will. Because the moment of value cocreation is unknown in advance, advance assessments of agency and affordance may be proven to be misjudgements once value cocreation is attempted in reality. S-D Logic focuses on the moment of value cocreation in situations where everything is in place for adherence, whereas it important also to consider possible inaccurate advance expectations of P-C value and ex post A-C value. It is also necessary to be aware that there may be contexts where resources are limited or missing. In such circumstances, the value cocreation process may not deliver the expected value-in-context. In addition, expected outcomes may not be achieved even when the planned behaviour commences. In the consumption moment, resources and/or agency may initially be present at a sufficient level to

start the process but not be enough to complete it. It therefore seems that A-C value judgements do not just take place before and after the P-C value-cocreating episode, but also during it.

However, a potential limitation of the Integrative Framework of Value model is that it does not explicitly explain its feedback loop. It perhaps suggests a loop straight back from *ex post* to *ex ante* A-C value assessments. This omits the early steps in the adherence process, so this understanding of the feedback loop would not fully explain how it may operate in practice nor where it feeds into future adherence decisions. However, on the assumption that such a loop feeds back into the process at appropriate points, this viewpoint could contribute to explaining changes to adherence over time.

### **6.2.6 Consolidation of S-D Logic**

After its evaluation in this chapter, it is concluded that S-D Logic has shown itself to be a potential basis for understanding adherence. Figure 14 depicted this. To extend the model to identify where the norms rule and perceptions of social support fit, the concept of occupying multiple service ecosystems and abiding by their institutions was introduced. Finally, the Integrative Framework of Value was considered as a means of understanding how at least a proportion of adherence may change over time.

Figure 17 is an attempt to understand how the concept of multiple service ecosystems with the Integrative Framework of Value might contribute to a greater understanding of adherence. Some comments on this diagram are necessary.

Firstly, since service ecosystems relate to norms and support, it seems reasonable to position them as forming part of the patient's consumption context. Because they contribute to the decision on whether to consume, it would be natural to place them between resources and the point of *ex ante* value assessment. This is to show that they are part of the context and to make their role in decision-making clear. However, on a more practical level this review is

likely to happen as part of the *ex ante* A-C value assessment and so for easier visualisation it may ultimately be simpler to place them there.

Secondly, it is clear that Ng & Smith's (2012) Integrative Framework of Value has P-C value at the point of value cocreation while A-C value *ex ante* and *ex post* are outside of the consumption context. To show this, Figure 17 adds two steps to the framework, one before and one after the adherence (value cocreation) step. Having positioned this, it is important to recognise that A-C value is also assessed during that process but that this by definition removes (perhaps only temporarily) the patient from the P-C value cocreation process. The Integrative Framework of Value implies a feedback loop, but its target is undetermined.

The diagram of S-D Logic is enhanced with these two constructs in Figure 17. This is referred to here as the initial process of adherence. From this diagram and the foregoing considerations seven points arise.

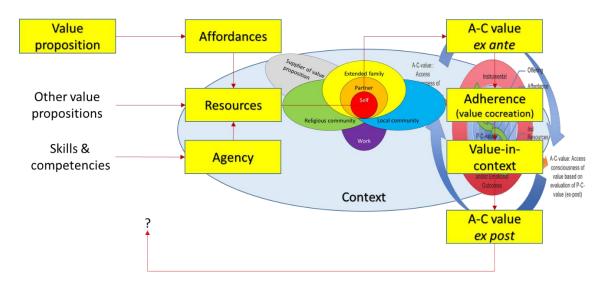


Figure 17: Enhanced diagram of S-D Logic: initial process of adherence

Firstly, the value proposition of the medicine must reach the patient if it is to be consumed. It must be provided at a cost which the patient can afford, and at a location which is attainable. This indicates that the patient's agency includes the means (money and ability to reach the point of supply) to acquire it.

Secondly, the patient must have a way of identifying one or more medicines which could meet their need in context, or in other words to know what value propositions are available and to perceive their affordances. Without this knowledge adherence is not possible.

Thirdly, the patient must perceive that they have sufficient agency – operant resources provided by their skills and competencies including motivation and beliefs – to be able to take the medicine, or in other words to act on the resources provided by the value proposition of the medicine in order to cocreate value. Without this perception of capability the adherence attempt may not commence.

Fourthly, the patient must perceive that they have all of the other value propositions in their context – the appropriate density of resources – which are required to successfully cocreate value. If the patient does not have, or does not perceive that they have, all the co-requisites in context then the adherence attempt is unlike to commence.

Fifthly, once the patient has the medicine, is motivated to consume it, and perceives that they have the agency, then they must assess the A-C value to decide whether to go ahead and attempt to cocreate value. This assessment will consider the perspectives of the multiple service ecosystems in which they exist and their connectedness to those ecosystems, and will weigh up the pros and cons of being adherent within each one of them. If their assessment is negative in relation to their most important service ecosystem then it is unlikely that adherence will commence.

Sixthly, once a decision has been taken to consume, the patient moves to execute the process of value cocreation in order to cocreate value-in-context or, in other words, to be adherent. At this point the perceptions of agency and resources are tested against reality. If agency is lacking, or resources are missing or are exhausted, then adherence will commence but will not be successful. If the rule of instructions is accurate and followed correctly then consumption is adherent and the supplier of the medicine would expect the patient, all things being equal, to cocreate the offered value-in-context from the medicine. However,

if instructions are incorrect or are not followed correctly then value cocreation may not be successful.

Seventh and finally, following value cocreation, the patient will assess the A-C value *ex post* to determine the nature and level of value created. This assessment will feed back in some way into future decisions to consume (*ex ante* A-C value assessment), and it seems likely that this assessment will contribute to the patient's experience for future adherence opportunities.

At this point it is not important to form a clear understanding of where the feedback loop from the *ex post* A-C value assessment might land. However, it is clear that such a loop is part of the patient's overall assessment process.

### **6.2.7 Service-Dominant Logic summary**

S-D Logic appears to provide a framework for understanding the process of adherence at the point of consumption which goes beyond that which expectancy-value behavioural theories can achieve. Some of what might be considered to be potential limitations of the framework seem to be addressed by the two later additions. Firstly, a greater understanding of context is provided by the notion of contradictory overlapping and nested service ecosystems; this is potentially a contribution to understanding the rule of norms. Secondly, a clearer picture of value assessment is offered by the Integrative Framework of Value.

# 6.3 Changes to adherence over time

Although this research emphasises adherence as a point-in-time opportunity to adhere or not, the consideration of the feedback loop within the Integrative Framework of Value provides the chance to raise some questions relating to adherence over time based on A-C value assessments. All changes over time may be assessed at any place in the adherence process, but perhaps there are three key places. Firstly through A-C valuation *ex post* after adherence is attempted. Secondly at the point of *ex ante* assessment before an adherence attempt. But thirdly, changes may only be identified at the point at which adherence is attempted, or in other words at the point of value cocreation.

If the patient changes then that may drive change over time. The patient is represented by agency, beliefs and motivation in this adherence research, so a change in the patient implies a change in one of these three factors. Such change may lead to higher or lower adherence and therefore affect the level of adherence at each opportunity to adhere.

If the medicine changes then this may lead to change. The medicine is represented by its affordances here. Therefore a change in medicine would mean a change in this factor. As before, this may increase or decrease point-in-time adherence at different times.

If the context changes then this may lead to change. The context is represented by the norms of in-focus service ecosystems and by the context itself. Changes to either of these could lead to an increase or decrease in point-in-time adherence at different times.

Through this brief assessment it is clear that it is profitable to think of adherence as an individual opportunity to consume since the many variables which contribute to being adherent are as constant as they can be at a point in time. Taking adherence to mean being compliant over the period of the course of treatment is also valuable, but of necessity it must average all the factors over time. This means that the detail of what happens at each adherence opportunity is inevitably missed. Building a greater understanding of what drives adherence requires deep knowledge of individual adherence attempts which is most easily achievable through qualitative research.

This perspective may help to explain why multiple-intervention studies often report limited success. By averaging adherence over a course of treatment – and especially over a cohort in quantitative research – while promoting various adherence interventions throughout the course, may show each intervention as being of limited benefit overall. By contrast, visualising adherence as a series of separate events may reveal that for each adherence opportunity a particular individual intervention is just what is required at that instant even though on average its effect is limited.

### 6.4 Summary

This chapter has evaluated S-D Logic and confirmed that it can form the basis for understanding the act of adherence. In addition, it can provide insights into the end-to-end adherence process. This permits theorisation of adherence beyond the expectancy-value theories.

It has also suggested that the Integrative Framework of Value can explain not only decision-making leading up to adherence, therefore potentially replacing those theories in this process view of adherence, but can also shed light on the thinking which takes place after the adherence attempt.

The inclusion of service ecosystems and their institutions has helped in understanding the complexity of decision-making due to the patient occupying multiple ecosystems simultaneously. It has also contributed an appreciation of both the sources of adherence-encouraging social support and the reasons why it might not be forthcoming.

The visualisation of S-D Logic with these elements included is an aid to moving beyond this point in the research.

# 7 Literature Review: Summary and Conclusions

### 7.1 Introduction

This chapter brings together the threads from the literature review and the analysis in the foregoing chapters and sets out the reasoning, justification and development of Qualitative Propositions for the next stage of this research, the qualitative empirical work.

The structure of the chapter is as in Figure 18.

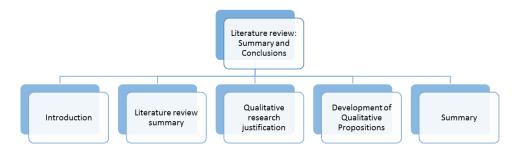


Figure 18: Chapter structure

# 7.2 Literature review summary

The basic working definition of adherence that was used to initiate this research was taking medicine according to instructions. The definition of consumption selected was that which relates to value in use rather than value in exchange. Value in use is to do with eating, drinking, coming into contact with services, and the like, rather than purchasing. In making this choice, research on economics and consumerism was excluded.

The review commenced with a survey of the definitions of adherence used in the healthcare sector. This review discovered that there is no single agreed definition of adherence. Instead, there are very many practice-based definitions used in research, both in practical empirical work and in more theoretical papers.

Firstly, it looked at adherence in healthcare other than medicine consumption. Some prior research was uncovered. Where theorisation was found it tended to be restricted to the immediate research scope with little attempt to expand it to inform any other adherence research. However, there was some contribution to thinking on the process of adherence. Although it tended to show that there was little assessment of the root causes of adherence or non-adherence, it did demonstrate that when there was it mainly talked about the importance of social pressure or support. In research which did invoke theory it tended to be Self-Efficacy Theory or the Theory of Planned Behaviour.

Interest then switched to medicine consumption. This was more fruitful in uncovering both reasons for non-adherence and also theorisation on why these might be. Firstly, the World Health Organisation report (Sabaté 2003) was found to be a mainstay of medicine adherence research, albeit at a practical level. Secondly, Adult Meducation (ASA & ASCPF 2006) was seen to build on this to identify and group 55 causes of non-adherence.

The review then progressed to review medicine adherence research. Over 1000 papers were found, according to Google Scholar (almost 19,000 in MEDLINE). Of these, about 45% (Google Scholar) or 1% (MEDLINE) of papers invoked a theory in support of their research, Taking account of a paper by Painter et al. (2008) which stated that almost 70% of research referencing a theory was actually influenced by theory rather than invoking it, this suggests that only around 16% (Google) or less than 1% (MEDLINE) of research actually uses theory as a foundation.

Several key themes were identified in the survey of medicine adherence papers. These were taken forward to contribute to developing the qualitative process of adherence.

Next was a discussion of limitations in current research. This highlighted that most research was performed in the developed world, that developing world research was largely about HIV/AIDS and, as restated above, most research was not underpinned by theory. In the exceptions to omitting theory, Self-Efficacy Theory or the Theory of Planned Behaviour were the most used. Other research included theories and models such as the Theory of Reasoned Action, the COM-B model, the Health Belief Model and the Children's Health Belief Model. These

were explored as a basis for later discussion, identifying particularly their inability to theorise the actual act of adherence and therefore the need to move beyond them.

Following that, an assessment was made of this body of literature's contribution to a theoretical process of adherence. This assessment identified that expectancy-value theories were used, that self-efficacy and social support were major determinants of adherence, that motivation and beliefs were also important in the patient's decision, and that medicine characteristics played a part.

Finally in the medicine adherence review, a chapter drew all these elements together to discuss the factors and to group them into three: the patient, the medicine and the adherence environment. It then analysed these groups before identifying the unit of analysis and the definition of adherence to be used in the rest of this research: the adherence opportunity afforded to a patient to consume a single dose of medicine in context.

Service-Dominant Logic was then considered as a means to understand both the single opportunity to be adherent and what actually happens in consumption. This builds on expectancy-value theories which cease theoretical analysis at the decision stage of the adherence process. The result of this exploration led to the creation of an initial theoretical process of adherence for use in qualitative research.

# 7.3 Qualitative research justification

The literature review demonstrated that there is no theoretical model which explains adherence throughout the process. Some theories help to envisage the early parts of the process focusing on motivation, but none are able to support an understanding of what happens at the point at which adherence should occur. This is a gap in the adherence literature.

An assessment of Service-Dominant Logic suggested that it could inform the consumption act within the adherence process, and potentially also augment or replace the theories which have hitherto been used to illuminate some of the

earlier stages of the adherence process. While qualitative studies of adherence have been performed, none have used the lens of S-D Logic as their basis or approached adherence as point-in-time opportunity to adhere. As Rathbone et al. (2016) state very clearly:

"Qualitative research enables rich, detailed data to be collected and analyzed, allowing novel perspectives to be generated and phenomenon to be explored at a fundamental level, ontologically and epistemologically. That is to say, qualitative research can help identify what a phenomenon 'is.' The need for this kind of fundamental qualitative research has been systematically identified in the adherence literature".

It is reasonable to state that it is still unclear what adherence "is". The research question remains unanswered: what is adherence from a process perspective? This remains the focus of this research.

Until Service-Dominant Logic was applied to the question of adherence there had been no suitable theoretical means to bring together patient, medicine and context. However, the initial process of adherence created from theory has not yet been shown to be reasonable in practice. This gap needs to be filled in order to determine whether in practice S-D Logic is a firm basis for a theoretical process of adherence. For this reason the thesis moves on to an exploratory exercise of qualitative research.

# 7.4 Development of Qualitative Propositions

It is not necessary to show through qualitative interviews that each of the inhibitors identified in the literature review actually exists in practice. Others' research has already shown this to be the case. What is necessary is to show that adherence can be explained in practice by this initial process. That is, the S-D Logic-based initial view of the process of adherence needs to be assessed through practical research before it can be considered to be a candidate to support a theoretical process view of adherence. To achieve this it is necessary

to evaluate whether the factors of adherence can be placed within the initial view via qualitative research.

The qualitative research therefore aims to do two things.

The first objective is to contribute that "rich, detailed data" of lived lives into the research process in order to gain a deeper understanding of adherence at the level of an individual opportunity to adhere. This has not been done before. One measure of its success will be whether this approach identifies further causes of non-adherence which can be added to list of 55 causes of ASA & ASCPF (2006), while another will be whether the interviews recognise the six factors of adherence. Success in this objective will provide support for the second.

The second objective is to show in practice that the initial view of the process of adherence is a valid means to understand adherence by showing that the non-adherence factors already discussed can be logically placed within it. This use of S-D Logic to explore point-in-time adherence through factors is new.

The first step in operationalising factors of adherence within this process view and testing them quantitatively was also taken. The quantitative research hypotheses are developed and justified in the chapter between the qualitative and quantitative research. However, the quantitative research was unsuccessful because of flaws in design and implementation.

# 7.4.1 Qualitative Proposition 1: identification of adherence factors and additional non-adherence causes

As indicated earlier, this first objective is to contribute rich, detailed data of lived lives into the research process in order to gain a deeper understanding of adherence at the level of the individual opportunity to adhere. While qualitative adherence research has been done before, it has not been done with the focus on the individual adherence opportunity.

The initial measure of its success will be that it covers all the ground of the six adherence factors identified in the literature review. This will help to confirm the validity of the interview data. This results in Qualitative Proposition 1a.

**Qualitative Proposition 1a**: It is possible to uncover all adherence factors within the interviews.

The second measure of its success will be whether this approach identifies further causes of non-adherence which can be added to list of 55 causes of ASA & ASCPF (2006) (Table 4). This results in Qualitative Proposition 1b.

**Qualitative Proposition 1b**: Further causes of non-adherence will be uncovered over and above the 55 causes already catalogued.

These Propositions are also intended to lend support to Proposition 2.

### 7.4.2 Qualitative Proposition 2: validation of the S-D Logic model

The use of S-D Logic to explore point-in-time adherence through factors is new and so it is necessary to confirm empirically that S-D Logic provides this support. Therefore the objective of the Proposition is to understand how the factors of adherence already discussed can be positioned within the initial process of adherence. If a model of placement, reasoned in advance, can be shown to be aligned with qualitative research then the model can be considered to be supported. This results in the second Proposition.

**Qualitative Proposition 2**: The initial adherence process derived from S-D Logic provides a foundation for the final qualitative process.

# 7.5 Summary

The chapter has provided a detailed analysis of the literature review, established the justification for performing qualitative research, and laid out the Propositions for that research. It has made the case for moving towards developing a process of adherence in at least two ways: current expectancy-value theories cannot explain the whole end-to-end adherence process; and there is a need to understand how so-called causes of non-adherence work out in patients' perspectives in their many and varied consumption contexts.

The research now moves on, firstly to an exploratory qualitative exercise with the aim of creating a structural qualitative view of the process of adherence, and

secondly to quantitative research in order to create a quantitative view of the adherence process and so operationalise major elements of adherence. These are introduced, reported on and analysed in Section B.

# **Section B: Moving Towards a Process View of Adherence**

### 8 Research: Introduction

### 8.1 Section introduction

Section B provides introductions, results, analyses, and conclusions for the empirical research.

It firstly explains and justifies the research philosophy, ontology, epistemology and methodology.

The method, results, analysis and conclusions of the qualitative work are then presented. The resulting qualitative process of adherence is the main result of this research.

Between the qualitative and quantitative research is developed the quantitative view of the process of adherence based on the qualitative research.

Following this are presented the methods, results, analysis and conclusions of the first test of the quantitative theoretical process of adherence. This first test of the model was intended to determine the possible contributions of quantitative analysis to understanding adherence. The quantitative process of adherence is the main result of this research; the quantitative results need to be treated with extreme caution.

Therefore the structure of this section is as per Figure 19.



Figure 19: Structure of Section B

# **8.2 Chapter introduction**

The purpose of this chapter is simply to introduce the research.

The structure of this chapter is seen in Figure 20.

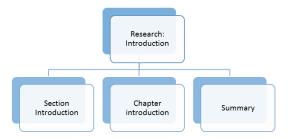


Figure 20: Chapter structure

# 8.3 Summary

This short introductory chapter has explained the structure of Section B of the thesis.

# 9 Research Philosophy, Ontology, Epistemology and Methodology

### 9.1 Introduction

This chapter describes the philosophical basis for the theory and practice of this thesis. This is Critical Realism. Having considered this, it moves on to the ontology and epistemology which emerge from this philosophy, and finally to the methodology for the research. This chain is documented and justified.

This chapter is therefore structured as in Figure 21.



Figure 21: Chapter structure

# 9.2 Why Critical Realism?

The overarching philosophical viewpoint taken for the research is Critical Realism (Bhaskar 2008; Bhaskar 1998).

This research entails learning from individuals about their own experiences. Therefore a philosophy is required which recognises that there exists a world which includes our socially determined knowledge about reality, while at the same time there is a world where adherence has a real definition which remains the same whether individuals recognise it or not. These two worlds exist in parallel, the external world independent of our experience of it and an internal world which is our understanding of adherence. In other words, patients have their own views of reality which may or may not match true reality but which nevertheless are real to them in the domain of the actual even if they do not reflect what another would recognise as their reality.

This view is supported by Critical Realism. Once this philosophy is chosen, ontology and epistemology are decided also.

# 9.3 Philosophy

Critical Realism emerges from scientific realism while recognising the importance of societal impact on science which thus requires the inclusion of researchers' engagement in their research. It therefore rejects positivism which assumes the researcher is completely dispassionate. Its aim is to synthesise two views of research, namely the social character of science and the stratification of science (Bhaskar 2008 p.xxx). One of its key claims is that (ibid. p.1):

"[N]ot only is a constant conjunction of events not a sufficient, it is not even a necessary condition for a scientific law".

Bhaskar (ibid. p.2-3) argues that Critical Realism requires that the three domains of "the real, the actual and the empirical are distinct", or as stated in reverse order by Danermark et al. (2001), "what we experience, what actually happens, and the underlying mechanisms that produce events in the world" are distinct. Bhaskar illustrates this by Table 6, reproduced from Bhaskar (2008 p.2). What this means is that there is a reality of "structures", "causal laws" or "tendencies" which exist independently of whether we know about them or not; there are events at the actual level which, if they arise, do so as a result of the causal mechanisms acting at the real level; and there are things which we may or may not perceive at the empirical level which are the result of the causal laws acting. In other words (ibid. p.7), "tendencies may be possessed unexercised, exercised unrealised, and realised unperceived (or undetected) by men".

Table 6: Real, Actual and Empirical, after Bhaskar (2008 Table 0.1)

	Domain of Real	Domain of Actual	Domain of Empirical
Mechanisms	٧		
Events	٧	٧	
Experiences	٧	٧	V

A constant refrain of Critical Realism is that of the difference between open and closed systems. Bhaskar (2008 for example p.23) points out repeatedly that only in closed systems where everything is held constant apart from the experimental variables do mechanisms reliably deliver the same results time after time, and so it is only for closed systems where predictions can reliably be made. In open systems there are multiple influences which cannot be held constant, so the same result cannot be assumed either to happen or not to happen for the same reasons each time. This is the basis of his point that constant conjunctions of events are neither necessary nor sufficient. The result of this is that science – physical and social - must seek for underlying explanations rather than just epistemological constancy. This provides justification for the qualitative social science research where people's realities, sometimes referred to as "perspectivism" because knowledge is local and contextual, can be collected and deeper structures inferred. While this approach may not enable a complete grasp of the real domain, it can at least help to make sense of the events which make up the actual domain - the working of people's perceptions of institutions acting or not acting to deliver experiences.

In this discussion is seen the influence of the open system of context on adherence. The patient's perceptions of themselves and the medicine are similarly a manifestation of the actual in the space of empirical – the perceptions may or may not be an accurate representation of the true reality. Considering the three rules, all could be said to exist in the real, but a patient's understanding of them is only an interpretation of the real as perceived in the actual space. There will then be an acceptance or rejection of them in the empirical space depending on whether they are acting in the patient's mind at the time.

# 9.4 Ontology

Bhaskar's starting point for science (Bhaskar 2008 p.13) is, "What must the world be like for science to be possible?". He shows that rather than focusing on epistemology we should be looking at ontology – the knowledge itself, and not how we discover it. Danermark et al. (2001) extend this viewpoint into the social

sciences by asking the question, "What properties do societies and people possess that might make them possible objects for knowledge?". This fits very well with much of Service-Dominant Logic including service ecosystems and institutions, where the institution can be viewed as existing in the domain of the real, and which may or may not act and may or may not be perceived by an individual. A particular ecosystem may or may not therefore affect someone's thinking depending on whether it is perceived and depending on whether it is "acting" in that person's life at that time. Each person has their own view of reality based on those two things, but there still remains the domain of the real which may or may not be accurately represented in a person's perceptions of the combination of service ecosystems/institutions.

Bhaskar takes things further. He points out (Bhaskar 2008 p.36) that:

"[generative] mechanisms endure even when not acting; and act in their normal way even when the consequents of the law-like statements they ground are, owing to the operation of intervening mechanisms or countervailing causes, unrealised".

Once more, this has echoes in Service-Dominant Logic such that, as has become apparent, a lack of resources (context, agency, affordances, etc) may prevent value cocreation even though the generative mechanism of motivation exists.

Another important element of Critical Realism is emergence. Bhaskar (1993 p.49) describes this as:

"In emergence, generally, new beings (entities, structures, totalities, concepts) are generated out of pre-existing material from which they could have been neither induced nor deduced".

There is a close parallel between Critical Realism and S-D Logic's concepts of service systems, where the system cannot be reduced its constituent parts but is emergent from them. Service systems in their complexity must be researched as wholes and not as sums of parts.

### 9.5 Epistemology

As indicated above, Critical Realism focuses on ontology rather epistemology. It takes the view that experiences are independent of the domain of the real, such that knowledge of an object is not the same as the object itself. It is therefore not possible to define something – mechanisms, causal laws, tendencies – only by what is perceived since they exist independently of the observer. This leads to an epistemologically cautious approach to knowledge, since true reality may not be easy or even possible to perceive.

It is important that the research gives the participants the full opportunity to present their views of reality without constraint or judgement. This implies that the research encompasses interpretivist and potentially constructivist perspectives as well. This fits well with Critical Realism's epistemological caution, which recognises that people have their own views of reality without these being the full reality – that is, all individual perceptions of reality are partial. These perspectives have therefore been fully recognised in the research.

# 9.6 Methodology

#### 9.6.1 Introduction

The methodology for this research must support the need to investigate the phenomenon of adherence in patients whilst taking account of the preceding discussions on ontology and epistemology. In order for the research propositions and hypotheses to be investigated, the methodology must permit an understanding of the phenomenon of adherence in the context of contemporary events while having no control of those events. It must encourage individuals to discuss the world as they see it without judgement, recognising that each patient's worldview is legitimate. Critical Realism supports this since it accepts that empirical experience of the real mechanisms acting at the actual level is different for each patient even though that reality does exist behind experience.

### 9.6.2 Chosen approach

The desires were twofold. Firstly, from the literature to build an initial process, from this derive Qualitative Propositions, and then to check the alignment of those Propositions with interview results. Secondly, to establish hypotheses from the qualitative research and explore them quantitatively. This led to the selection of a mixed methods approach to a case study.

Case studies support a range of methods which can be triangulated together to deliver research results. Yin (2013 p.16) defines the case study as:

"...an empirical inquiry that: investigates a contemporary phenomenon ("the case") in depth and within its real-world context... especially when the boundaries between phenomenon and context may not be clearly evident".

It is not desirable to perform experiments on patients. Nor is it possible to control for variables when there are so many, both known and unknown, in the open system of the world. Even if it were possible, solely using such an approach would only permit the testing of pre-determined causes of non-adherence; part of the research has been to uncover currently unknown or undocumented causes.

The requirements led to research in two parts. Input to the qualitative research was the initial process of adherence which was developed from an analysis of the literature on patient, medicine, context and the three rules. The qualitative research took this initial view and generated Qualitative Propositions. It then explored these propositions in the case of medicine adherence, obtaining a rich knowledge of adherence in lived lives through interviews in order to recognise known non-adherence causes and to identify new causes. From this it created a quantitative process and evaluated the quantitative hypotheses by means of a survey. Sadly, the quantitative hypotheses were not supported as a result of imperfect design and implementation of the survey.

These requirements led to the choice of semi-structured interviews or "guided conversations" (Yin 2013 p.110) to obtain "insights, explanations, and meanings related to certain occurrences" (ibid. p.111).

Qualitative research is valuable in order to explore the "why" and the context, and such supports the perspective of Critical Realism. As Yin (2013 p.16) says,

"A case study is an empirical enquiry that

- investigates a contemporary phenomenon (the "case") in depth and within its real-world context, especially when
- the boundaries between phenomenon and context may not be clearly evident".

This therefore permits the building and refining of theory in parallel to data analysis because it permits a focus on reasons rather than just outcomes. As Dubois & Gadde (2002) state:

"... we have found that the researcher, by constantly going 'back and forth' from one type of research activity to another and between empirical observations and theory, is able to expand his understanding of both theory and empirical phenomena".

This process is referred to as retroduction or abduction (Mingers et al. 2013). Therefore, this approach is perfect for creating and validating conceptual processes qualitatively.

There are several possible options to defining a case. The simplest is a single-case study with field research performed in one location. Beyond that is a two-case study, which opens up several possibilities. The first is field research performed in two similar locations in one country; the second is two different locations in one country; the third is two similar locations in two countries; the fourth is two different locations in two countries. "Different" here relates to elements which may affect adherence.

Initially, a perspective was taken that there would be significant differences in the issues found in the developed and developing worlds. Therefore the fourth

approach to the case study was taken. In the qualitative interviews it was quickly discovered that this was not the case. Although some differences emerged due to the natures of the two environments of the developed world of UK and the developing world of (primarily) sub-Saharan Africa, there were also strong overlaps and equivalences in findings. Therefore the third approach was substituted for the fourth, the two environments being treated as essentially the same. This meant that no breakdown of the two locations was performed during analysis.

The analysis approach for the qualitative research was aimed at examining the validity of the initial process. The quality of the interview results was tested in two ways. Findings from the multiple sources and literature were triangulated. A Critical Realist-aligned approach based on Systematic Combining (Dubois & Gadde 2002; Dubois & Gadde 2014) was used to develop conclusions. This permitted an assessment of the initial adherence process emerging from the literature review, and its refinement into what is referred to as the qualitative process of adherence.

A first step was taken towards analysing the qualitative process of adherence quantitatively by use of a survey. A significantly simplified view of the adherence process, the quantitative view, was constructed for statistical analysis. Statistical techniques were used in an attempt to understand the interactions of the factors assessed in the survey. This did not lead to definitive results, but provided useful pointers for future steps if thought desirable.

### 9.6.3 Conclusion

The research method selected was a mixed methods approach of qualitative research to explore the validity of and to extend the initial view in order to create a qualitative theoretical process, followed by quantitative research to evaluate a quantitative viewpoint.

# 9.7 Summary

A combination of mixed methods – qualitative semi-structured interviews and quantitative survey – was used to support the selected philosophy with its resultant ontology and epistemology. The methodology supports this approach.

### 10 Qualitative Research Method

### 10.1 Introduction

This chapter considers methods used in the qualitative research, namely the use of qualitative semi-structured interviews. It starts with an overview of the approach followed by more detailed explanations of the methods used in investigating the two Qualitative Propositions. It shows the alignment of the qualitative work with the propositions.

The structure of the chapter is as in Figure 22.



Figure 22: Chapter structure

# 10.2 General approach

A series of semi-structured interviews was arranged with people who were willing to talk about their past experience of taking medicines. They were located in various environments ranging from a comfortable urban environment in a developed country through to an impoverished rural environment in a developing country. Much thought was put into how to cover both the developing and developed world with a range of ages and in a variety of situations.

Interviewees were selected using purposive sampling (Teddlie & Yu 2007). Initial interviews were performed with contacts in UK. Following that, interviews were arranged with contacts in a range of developing countries including Kenya, Tanzania, Kazakhstan and Nigeria. These were intended to explore situations in the developing world, primarily sub-Saharan Africa. This purposive sampling was aimed at obtaining information from "a broader group of cases" and to enable "comparisons among different types of cases" (ibid.). It therefore made use of

both typical case sampling and outlier sampling since it included interviewees at all stages of life in both developed and developing world environments.

Over time, further interviews were performed in countries other than those mentioned above in order to build the widest picture and to understand their relationship to the initial findings. Most of the later interviews used snowball sampling, with earlier interviewees encouraging their acquaintances to participate, but typical case and outlier sampling methods continued to be used where the opportunity arose.

A total of 30 interviews were performed over a period of just over 5 months from the end of December 2014 to early June 2015. Table 40 in Appendix B.4 provides a detailed list of interviewees. All interviewees were given the opportunity to review the Participant Information Leaflet (Appendix B.1) and to confirm their willingness to participate via the Consent Form (Appendix B.2). The ethics of the approach were approved by BSREC through Warwick Medical School (Appendix B.3).

Some interviews were performed face to face but most were by phone or by exchange of written lists of questions and responses. For face-to-face and phone interviews, recordings were made using a recording application on a mobile phone. Most interviews lasted for about 25 minutes. Nvivo10 and manual means were used to extract and code these interviews from the full transcripts. Coding can be found in the tables in Section 11.3 and Appendix B.6. Since the purposes of the interviews were to gain qualitative insights in support of Qualitative Proposition 1 and to assess interview validity in support of Qualitative Proposition 2, it was not important that every conceivable combination of age, environment and country be included in the research as long as the research was indeed robust. The general approach of Systematic Combining (Dubois & Gadde 2002; Dubois & Gadde 2014) was used to revise the initial process based on empirical findings.

Interviews were perused line-by-line to identify and extract phrases. These were then both assigned against the eight subordinate propositions of Qualitative Proposition 2, and as reasons for and against taking medicine in support of Propositions 1a and 1b.

# 10.3 Qualitative Proposition 1

The purpose of this Proposition is to assess the quality of data emerging from the qualitative interviews in support of Proposition 2. In addition, it might be expected that deeper, though unmeasurable, value would be found in the interviews beyond these quantifiable assessments. The Propositions are restated here.

**Qualitative Proposition 1a**: It is possible to uncover all adherence factors within the interviews.

**Qualitative Proposition 1b**: Further causes of non-adherence will be uncovered over and above the 55 causes already catalogued.

The propositions are stated quantitatively since otherwise they may be open to counterargument.

The interview transcripts were assessed in two different ways to investigate these propositions. Both analyses were done separately for developed and developing worlds as a means of comparison before being brought together. The initial assumption was that there would be large differences between the results of the "control" interviews of UK interviewees and the developing world interviewees. In fact, it was discovered that there were very few differences, thus permitting the amalgamation of the results.

### 10.3.1 Qualitative Proposition 1a

For Proposition 1a, the interview extracts were brought together under dataderived codes. These codes were then consolidated in categories with positive and negative attributes for each. These were then further grouped in a taxonomy. Without changing their meanings, the labels of the taxonomy were then revised to match the naming convention of the adherence factors.

#### 10.3.2 Qualitative Proposition 1b

For Proposition 1b, the interview extracts were perused for causes of non-adherence. These interview causes were then compared against the 55 causes for non-adherence (ASA & ASCPF 2006). Each interview cause was recorded along with the interviews which mentioned them. Causes in the 55 not found in the interviews, and causes in the interviews not found in the 55, were then presented.

### 10.4 Qualitative Proposition 2

The second proposition developed for the qualitative research was:

**Qualitative Proposition 2**: The initial adherence process derived from S-D Logic provides a foundation for the final qualitative process.

The approach taken was first to establish a potential positioning of adherence factors within the initial process and then to assess this positioning through interviews.

It is necessary to consider the six factors of motivation, beliefs, agency, affordance, consumption context and norms. Some of these factors may be applied to the initial view in multiple places while some elements of the process may support more than one factor being applied. Each factor will be positioned in turn.

Firstly, motivation. This is an attribute of the patient which contributes to their agency. It may therefore be placed within the process prior to Agency. It may also be present in the decision on whether to consume so could therefore also be placed on the A-C value *ex ante* assessment, and be present in the *ex post* assessment also. Because motivation is likely to affect earlier decisions, additionally it may be present in the choice as to whether to obtain the medicine.

Secondly, beliefs. This is a rule within the patient which contributes to their agency and so may be placed in the same places as motivation. It may also be present in the decision on whether to consume so could therefore also be placed

on the A-C value *ex ante* assessment, and in the *ex post* value assessment. As with motivation, it may contribute to whether the medicine is obtained.

Thirdly, agency. This the source of the patient's resources which are brought into the consumption context and so can be placed on Agency. It may also be present in the decision on whether to consume and whether to consume again so could therefore also be placed on the A-C value *ex ante* and *ex post* assessments. It may also be involved in actually identifying the appropriate medicine to obtain, and therefore may be placed between the medicine's Value Proposition and its Affordances.

Fourthly, affordance. This is the source of the medicine's resources which are brought into the consumption context and so may be placed on Affordances. Since affordance also includes costs, both financial and access-related, it may also be present in the medicine's Value Proposition. Also, since costs may be included in the *ex post* assessment of value, affordance may also be placed at this point.

Fifthly, norms. These are rules within the context which are taken into account by the patient when making a decision to consume and so may be overlaid onto the picture of service ecosystems. The positioning of service ecosystems within the consumption Context was done in order to emphasise that they are part of that context, but they contribute to the A-C value *ex ante* assessment and potentially the *ex post* assessment also. Therefore although the placement of norms appears to be correct it may be appropriate to consider it to be part of that *ex ante* and *ex post* assessments and so be placed there instead.

Sixthly, context. This is obviously the consumption Context. It also encompasses contributions to context of other value propositions required to consume the medicine.

Seventh and finally, the process of value cocreation must be brought into the picture since this represents consumption. This is present as Adherence in the view of the process.

These possibilities can be enumerated, if necessary grouped, and then tentatively applied to the initial process ready for testing their alignment with interview content. The resulting application can be seen in Figure 23, and are described in detail below.

Group 1 represents the costs of obtaining the medicine and relates to the medicine's value proposition, leading to its affordance. It also represents the levels of motivation and beliefs of the patient.

Group 2 represents the patient's motivations and beliefs as they are applied to medicine consumption.

Group 3 represents the agency of the patient in being able to identify the correct medicine, and the affordability of the medicine which therefore contributes to its affordance.

Number 4 represents the sum total of the patient's agency brought into the medicine consumption context.

Number 5 represents the contribution of all the value propositions other than the medicine which are required for the patient to consume the medicine.

Number 6a represents the norms which contribute to the consumption decision. Norms is part of the context but also contributes to the decision so number 6 is split into two parts.

Group 6b represents the motivation, beliefs and agency which contribute to the consumption decision in relation to the medicine's affordance, perception of the norms and the anticipated context. Considering number 6 as being in two parts shows that both parts operate together.

Number 7 represents the actual consumption event, or value cocreation. This entails a coming-together of patient and medicine in context, thus engaging all factors at once.

Number 8 represents the *ex post* assessment of value based on the realities of motivation, beliefs and agency together with affordance, norms and context.

The three purposes of the qualitative research as related to these factors are to investigate whether these placements are valid, to determine whether they represent the three constructs in a feasible way, and to explore them in depth. The interviews will contribute to this by helping to ascertain whether the suggested factors are present in each group, thus supporting the alignment of Qualitative Proposition 2 with the reality of the interviews.

As a working model of these placements, Figure 23 represents the foregoing groupings which can now be assessed qualitatively.

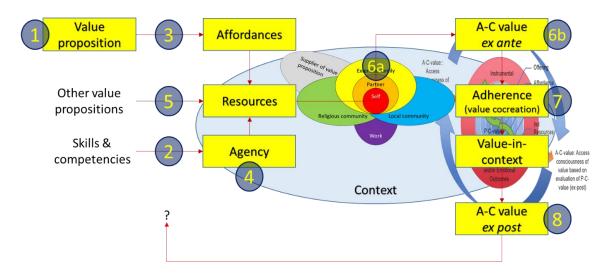


Figure 23: Initial process with group placements

More formally, Qualitative Proposition 2 can be allocated its own subordinate propositions within the overall proposition. Since these placements represent potential inhibitors or enablers of adherence, these subordinate propositions will take that perspective in order to evaluate the underlying reasons for each, thus linking each with the factors that they include. Therefore the subordinate propositions propose that each of the placements is correct and are made up of the factors discussed. This approach leads to the subordinate propositions listed in Table 7. These are referred to as "S1", "S2", etc. These subordinate propositions were used as input to the interviews.

**Table 7: Subordinate propositions for Qualitative Proposition 2** 

No.	Stage in the process	Enabler/inhibitor
S1	Obtaining the medicine	The costs of obtaining the medicine, both money and time – medicine affordance, patient motivation and beliefs
S2	Contribution to agency	The patient's motivations and beliefs
S3	Identification of	The patient's agency identifying the correct
	medicine	medicine/affordances of the medicine
S4	Perception of agency	Total of agency
S5	Availability of items in	The context containing all required for medicine
	context	consumption
S6a	A-C value assessment	The patient's recognition of norms in taking the
	ex ante	consumption decision
S6b		The patient's motivation, beliefs and agency in taking the
		consumption decision, in relation to the medicine's
		affordance and the context
S7	Value cocreation (P-C	The patient's motivation, beliefs and agency
	value)	The medicine's affordances
		The context and norms
S8	A-C value assessment	The patient's motivation, beliefs and agency with respect to
	ex post	the medicine's affordances, and the context and norms

## 10.5 Development of research questions

Based on the approaches, a set of questions was developed to explore the six factors. These are listed in Table 8. The table shows the linkage between the questions and the subordinate propositions, but the same questions also supported investigations into non-adherence. Asking a range of questions which, although supportive of the propositions did not map one-to-one, allowed a richer picture of interviewees' experiences to emerge.

Table 8: Questions referenced to subordinate propositions

Research question	Subordinate proposition reference
What medicine do you wish to share your experiences of? Please	
comment separately for each medicine	
Is this your first time with this medicine or is it a repeat prescription?	S1, S3, S8
How far was it to a pharmacy?	S2
How much did it cost you to buy the medicine?	S1
Did you obtain the medicine?	S1, S2, S6b
If you obtained the medicine, how did you feel about it at the time?	S4, S8
Did you actually plan to consume it in line with the prescription?	S2, S8
Did you know how to take this medicine? How do you know?	S7
Please describe your physical surroundings on various occasions	S1
when the prescription said you should consume? Who and what	
was there and not there?	
What were you thinking and feeling?	S4
How were your physical and mental health?	S4, S6a
Did you actually consume at that time?	S6a, S7
What helped you to consume or prevented you from consuming?	S1, S5, S6, S8
Is there anything about the medicine that makes it hard for you to	S1, S4, S5, S6b,
take it? What would make it easier for you?	S7,S8
If you had the choice, how would you like to take this medicine?	S7, S8
Anything else you want to say about what makes it easy or difficult to take medicines for you personally?	S1, S4, S5, S6a, S7

## **10.6 Summary**

A two-case study was used to investigate the Propositions and the initial view of the process of adherence. 30 interviewees contributed their input, which was transcribed to form the basis for analysis of reasons for non-consumption. Through this approach, working propositions were generated in order to derive analytic generalisations (Yin 2013 p.41) so as to compare the qualitative research against the initial process. The research explored the level and nature of constraints and their impact on adherence in order to create and assess any new findings.

For potential future research results were separated into the two types of context: developed and developing worlds. Following the discovery that the results emerging from both contexts were essentially the same, this separation was not used in the main research in this thesis.

# 11 Qualitative Research Results and Analysis

#### 11.1 Introduction

This chapter records and analyses the results of the qualitative research. Its purpose is to determine from the results whether the Qualitative Propositions align with the results. After an initial discussion of overall results, it firstly analyses results for Propositions 1a and 1b then secondly the results for Proposition 2.

It is therefore structured as in Figure 24.



Figure 24: Chapter structure

#### 11.2 Initial discussion

Table 9 provides a summary of interviewees categorised in several ways.

A total of 30 interviews were performed over a period of just over 5 months from the end of December 2014 to early June 2015. Table 40 in Appendix B.4 provides a detailed list of interviewees. The range of interviewees was purposively sampled to obtain views from different age ranges and types of location. While the USA is not represented, the developed world viewpoint is present in the UK interviews. In addition, the developing world, represented in the main by sub-Saharan Africa, was not focused on HIV/AIDS like the majority of Africa-based research has tended to be. The interviews therefore should be able to contribute fresh perspectives to the adherence debate.

**Table 9: Summary of interviewees** 

Category	Value	Number of interviewees
Sex	Male	11
	Female	19
Age range	<20	1
	20-40	12
	40-60	10
	>60	7
World - developing	Total	24
	Of which:	
	• Egypt	1
	Kenya	14
	Kazakhstan	1
	<ul> <li>Nigeria</li> </ul>	1
	Tanzania	4
	Uganda	1
	Zambia	1
	Zimbabwe	1
World – developed	UK	6
Type of location	City	3
- <b>,</b>	Town	9
	Village	18
Medicine	Antibiotics	5
	Cough medicine	2
	Malaria medicine	11
	Painkillers	4
	Other	8
Medicine cost	Free	6
	<£1	8
	£1-£2	6
	£2-£3	2
	>£3	3
	Unstated	5
Distance to obtain medicine	<1km	8
	1-2km	11
	3-4km	3
	5-6km	4
	>7km	2
	Unstated	2

Some of the developing world interviewees were highly impoverished, as some interview content demonstrated. For example, interviewee KN04 was just one who mentioned the problem of being adherent when they were too poor to afford three meals per day. Their role as interviewees was only permitted by use of either very basic mobile phones or borrowed phones. However, such contextual restrictions were not confined to the developing world: UK01 said that at times they did not have water to consume their medicine. As can be seen, interviewees in both UK and Africa shared the majority of causes of non-adherence.

## 11.3 Qualitative Proposition 1

### 11.3.1 Proposition 1a

This proposition focuses on interview coverage with regard to the adherence factors emerging from the literature review and used as part of the Proposition 2 discussions. The purpose is to determine whether the interviews contained all six factors.

The raw material for the analysis required for this Proposition will be found in Table 41 and Table 42 in Appendix B.6. These tables list transcript codes derived from the data, examples of interview extracts, and interview reference codes. The results of bringing together all the transcript codes together will be found in Table 10. These are simply the raw codes copied from those tables to permit a move towards focusing on the coding and away from the detailed interview content. Codes consist of a category followed by "positive" or "negative" to indicate whether code assists or inhibits consumption, followed by detail of the effect.

Table 10: Coding of interviews – random order

Code	Code
Distance, positive, close	Beliefs, positive, others
People, positive, present	Instructions, negative, unclear, written
Content, negative, unknown	Regimen, positive, acceptable
Motivation, positive, last resort	Regimen, negative, complex
Cost, positive, low	Regimen, negative, forgot
Instructions, positive, clear, written	Instructions, negative, unclear, verbal
Reminder, positive, alarm	Routine, negative, absent
Taste, negative, bitter	Routine, positive, present
Size, negative, big	Cost, negative, herbal, low
Formulation, negative, injection	Beliefs, negative, value
Effects, negative, side, specific	Stop, negative, busy
Taste, positive, sweet	Storage, negative, unsafe
Distance, negative, far	Instructions, negative, foreign language, verbal
Beliefs, negative, others, stigma	Instructions, negative, foreign language, written
Food, positive, present	Utensils, negative, missing
Food, negative, absent	Branding, positive, known
Beliefs, negative, foreign origin	Diagnosis, negative, foreign language, verbal
Beliefs, negative, lack of faith	Taste, negative, bad
Course, negative, long	Effects, negative, bad
Stop, negative, replaced by other	Effects, negative, side, general
Stop, negative, run out	Beliefs, negative, others, too dependent
Stop, negative, keep	Beliefs, negative, profit, pharma
Beliefs, positive, stay well	Beliefs, negative, profit, herbal
Beliefs, positive, get well	Stop, negative, better
Regimen, negative, unacceptable	Effects, positive, others
Cost, negative, high	Effects, negative, others
Instructions, negative, misunderstood	Stop, negative, discarded
Instructions, positive, clear, verbal	Access, negative, hard
Course, positive, acceptable	Formulation, positive, liquid
Water, negative, absent	Regimen, negative, unexpected
People, negative, absent	Smell, negative, bad
Water, positive, present	Beliefs, positive, confidence
Formulation, positive, injection	Size, positive, small
Beliefs, negative, pointless	Effects, positive, side, none
Reminder, positive, general	Access, positive, easy
Formulation, positive, tablet	Motivation, negative, tired

The first step in making sense of the interview codes is to group them by category. This is done in Table 11. The first term in each code defines the coding category, then each category is split into positive and negative attributes. The table is then created from these groups.

Table 11: Coding of interviews – grouped by category

Coding category	Positive attributes	Negative attributes
Distance	close	far
Access	easy	hard
Cost	low	high
		herbal, low
Diagnosis		foreign language, verbal
Instructions		foreign language, verbal
		foreign language, written
	clear, verbal	unclear, verbal
	clear, written	unclear, written
		misunderstood
Utensils		missing
People	present	absent
Content		unknown
Norms		others, stigma
Branding	known	, ,
Beliefs	others	others, too dependent
	confidence	lack of faith
		foreign origin
		profit, pharma
		profit, herbal
		value
		pointless
Motivation	last resort	
	stay well	7
	get well	7
		tired
Stop		keep
'		replaced by other
		discarded
		better
		busy
		run out
Effects	others	others
	side, none	side, general
	,	side, specific
		bad
Taste		bad
	sweet	bitter
Formulation	tablet	
	liquid	7
	injection	injection
Regimen	,	unexpected
- 3	acceptable	unacceptable
	'	complex
		forgot
Reminder	general	Ť
	alarm	7
Water	present	absent
Food	present	absent
Size	small	big
Smell		bad

Coding category	Positive attributes	Negative attributes
Course	acceptable	
		long
Routine	present	absent
Storage		unsafe

Table 11 permitted the identification of several similar categories. These were used to create a simple taxonomy. This is shown in Table 12.

Table 12: Categories grouped into taxonomic categories

Taxonomic categories	Categories		
Product-related	Content, Branding, Effects, Taste, Formulation, Size, Smell, Instructions, Regimen, Distance, Access, Cost, Diagnosis		
Environment	People, Utensils, Reminder, Water, Food, Storage, Norms		
Patient-related	Course, Routine, Stop		
Beliefs	Beliefs		
Motivation	Motivation		

Assessing these major taxonomic categories, they were compared with the initial process, Figure 17. From this it is possible to align each one with more recognisable categories. This is shown in Table 13.

Table 13: Taxonomic categories converted to process terminology

Category	Common terminology
Motivation	Motivation
Patient-related	Agency
Environment	Context, Norms
Product-related	Affordance
Beliefs	Beliefs

Finally, comparing this taxonomy in Table 13 with the initial process, it is possible to see all six adherence factors present. This bottom-up analysis of interviews implies that the interviews had good coverage of the six factors. It suggests that Proposition 1a has good alignment with the interviews.

#### 11.3.2 Proposition 1b

This Proposition requires the analysis of interview responses and their comparison with the five dimensions from Sabaté (2003) and the list of 55 causes of non-adherence from ASA & ASCPF (2006). This was performed by extracting all stated reasons for non-adherence found in the interviews. The tables below list the interviews which manifest those causes.

This analysis of the "Dimension" tables below indicates that all but ten of the 55 causes were seen in the interviews. This suggests that the interviews achieved good coverage of the main causes of non-adherence. It is perhaps understandable that those which were not in interviews are missing as a result of them either requiring the interviewee to expose themselves to what may be an unacceptable degree or needing to be inferred by the interviewer. For the second type, on-the-ground observations and interviews with medical staff would have assisted in their identification.

Table 14: Comparison of previously identified inhibitors with research – 1

Social and Economic Dimension	Seen in interview
Limited [relevant] language proficiency	EG01 KS01 UK02
Low health literacy	KN03 KN04 KN07 KN08 KN11 KN13 KN14
	UK01
Lack of family or social support network	KN08 KN11 UK01 UK02 ZI01
Unstable living conditions; homelessness	
Burdensome schedule	KN03 UK01 UK02
Limited access to health care facilities	KN03 KN07 KS01 TZ04
Lack of health care insurance	EG01
Inability or difficulty accessing pharmacy	KN03 KN04 KN07 KN08 KN10 KN11 KN12
	KS01 TZ01 TZ04 UG01
Medication cost	KN03 KN04 KN08 KN09 KN10 KN11 KN12
	KN13 KN15 KS01 NG01 TZ02 TZ04 UG01
Cultural and lay beliefs about illness and	KN05 TZ02
treatment	
Elder abuse	

Table 15: Comparison of previously identified inhibitors with research – 2

Health Care System Dimension	Seen in interview
Provider-patient relationship	EG01 UK05
Provider communication skills	KS01 UK04 UK05 UK06
Disparity between the health beliefs of the	EG01 NG01 UK05 ZM01
health care provider and those of the patient	
Lack of positive reinforcement from the	UK01 UK05
health care provider	
Weak capacity of the system to educate	UK05
patients and provide follow-up	
Lack of knowledge on adherence and of	UK05
effective interventions for improving it	
Patient information materials written at too	EG01 KS01
high literacy level	
Restricted formularies; changing medications	KN01 KN03 KN08 KN09 KN13 NG01 TZ02
covered on formularies	UK04 ZM01
High drug costs, copayments, or both	KS01
Poor access or missed appointments	KN03 KN07 KN08 KS01 TZ01 TZ04 UK04
Long wait times	UK04
Lack of continuity of care	

Table 16: Comparison of previously identified inhibitors with research – 3

Therapy-Related Dimension	Seen in results?
Complexity of medication regimen	KN12 KS01 TZ04 UK01 UK04 UK05 UK06
	ZM01
Treatment requires mastery of certain	UK01
techniques (injections, inhalers)	
Duration of therapy	KN03 KN04 KN07 KN09 KN11 KN13 KN14
	UG01
Frequent changes in medication regimen	KN03 UK04
Lack of immediate benefit of therapy	KN03
Medications with social stigma attached to	KN03 TZ02
use	
Actual or perceived unpleasant side effects	EG01 KN01 KN03 KN04 KN06 KN07 KN08
	KN10 KN11 KN12 KN15 NG01 TZ02 TZ03
	TZ04 UG01 ZI01 ZM01
Treatment interferes with lifestyle or requires	KN03 KN15 TZ04 UK01 UK02
significant behavioral changes	

Table 17: Comparison of previously identified inhibitors with research – 4

Condition-Related Dimension	Seen in interview
Chronic conditions	KN04 KN15 KS01
Lack of symptoms	KN01 KN03 KS01 TZ01 TZ03 TZ04 UK05
	ZM01
Severity of symptoms	KN04 KN08 KN09 KN12 KN14 KN15
Depression	KN09
Psychotic disorders	KN10
Mental retardation/developmental disability	

Table 18: Comparison of previously identified inhibitors with research – 5

Patient-Related Dimension	Seen in interview
Visual impairment	
Hearing impairment	
Cognitive impairment	
Impaired mobility or dexterity	
Swallowing problems	KN01 KN03 KN04 KN08 KN09 KN11 KN13 UK04 UK06 ZM01
Knowledge about disease	KS01 NG01
Perceived risk/susceptibility to disease	KS01 UK04
Understanding reason medication is needed	EG01 NG01 TZ04 UK05 ZM01
Expectations or attitudes toward treatment	KS01 TZ01 TZ04
Perceived benefit of treatment	EG01
Confidence in ability to follow treatment	EG01 KS01
regimen	
Motivation	EG01 KN01 KN03 KN07 KS01 TZ01 TZ02 UG01 UK01 ZM01
Fear of possible adverse effects	EG01 KN01 KN03 KN06 KN07 KN08 KN11 KN12 KN15 NG01 TZ02 TZ03 TZ04 UG01 ZI01 ZM01
Fear of dependence	
Feeling stigmatized by the disease	KN03 TZ02
Frustration with health care providers	
Psychosocial stress, anxiety, anger	KN10 KN12
Alcohol or substance abuse	

However, as expected as a result of performing interviews in UK and sub-Saharan Africa rather than USA, even as comprehensive a list as the 55 causes did not capture all causes emerging from the interviews. Table 19 lists those of the 55 causes not in the interviews on the left, and those found in interviews which are not in the 55 causes on the right. Sample interviews where the latter were found are also shown. This table supports Proposition 1b. The interviews have uncovered 19 new reasons for non-adherence beyond the 55 causes.

Table 19: Comparison of ASA & ASCPF (2006) and research findings

In ASA & ASCPF (2006)	In this research but not ASA & ASCPF	Seen in
but not this research	(2006)	interview
Unstable living conditions	Concern with medicine content	EG01
Elder abuse	Verbal instructions in foreign language	EG01
Long wait times	Written instructions in foreign language	EG01
Lack of continuity of care	Pharmaceutical industry profits	EG01
Depression	Herbal medicine industry profits	EG01
Psychotic disorders	Feeling better	KN03 UK05 TZ01
Mental retardation	Lack of food	KN03 KN04 TZ01
Visual impairment	Lack of water	KN08 UK01
Hearing impairment	Concern that medicine is of foreign origin	NG01
Alcohol/substance abuse	Lack of faith leading to need for medicine	TZ02
	One medicine being replaced by another	KN03
	Medicine kept for future occasions	KN03 NG01 TZ01
		UK05
	Medicine kept for family need	KN03 NG01 TZ01
	Instructions misunderstood	UK01 KN05
	Difference between written and verbal	KZ01
	instructions	
	Lack of routine	UK01
	Lack of safe storage	TZ04
	Forgetfulness	KZ01 TZ03
	Run out of medicine	UK04

Similar causes of non-adherence were seen in both developing and developed worlds. For example, a lack of food and water for taking tablets was mentioned in both environments yet these reasons were not mentioned in the list of 55 causes. This suggests that interviews are of significant importance both to understand non-adherence reasons in detail and also to expand the list of known reasons. Extending the list is not easy with quantitative surveys.

# 11.4 Qualitative Proposition 2

The coding of interview extracts against the subordinate propositions and by adherence factors is shown in the eight tables below. These are examples of content, not necessarily a full list of extracts per subordinate proposition.

Table 20: Interview content matched to S1, Obtaining the medicine

No.	Factor	Interview example	Interview
			code
S1	Motivation	Just down the road from our flat	EG01
		I used it as a last resort	KN01
		I have to go 4km away	KN02
		I'm distressed for getting better	KN03
		5km from home. Travelled by Nissan	KN04
		I found [it] after going to various pharmacy shops	KN07
		after moving to the third shop I did obtain the medicine	KN08
		used a motorbike	KN13
		4 hours [to get medicine]	TZ01
	Belief	the branding just makes you trust it more	EG01
		I had confidence that it will relieve my pain	KN09
		Felt good because I had been informed about its	KN10
		advantages	
		Hopes came with the prescription	KN13
		I knew soon I would be well	KN14
	Affordance	We pay. At the hospital sometimes we don't pay	KN02
		Ksh450 [£3.01]	KN11
		Ksh300 [£2]	KN13
		Fairly expensive for Kazakhstan	KZ01
		When you're attacked by malaria it's whether you can	TZ04
		rush to the pharmacy to buy	
		Some cannot afford the full dose	TZ04

Table 21: Interview content matched to S2, Contribution to agency

No.	Factor	Interview example	Interview code
S2	Motivation	I wouldn't [finish the course] even if the GP said "make sure you finish the course"	EG01
		I wanted to get relieved	KN07
		Because the medicine is so bitter, drop it from taking the whole dose	TZ04
		I never want to take drugs	UK04
		just don't want to take medicine at all	ZM01
	Belief	I don't know really what I'm taking tablets for	UK05

Table 22: Interview content matched to S3, Identification of medicine

No.	Factor	Interview example	Interview
			code
S3	Agency	You don't have a clue, they've given you a bottle, you can't speak the language	EG01
		I knew how to take them	KN04
		I knew by the doctor's prescription and advice	KN12
		This particular medicine and another one cost more expensive	KZ01
		I just get the diagnosis and I go for other medications	ZM01
	Affordance	It was in Arabic	EG01
		I had to ask my parents to decode the curvier writing	KZ01
		If you don't have money you can just take some local medicine	TZ04

Table 23: Interview content matched to S4, Perception of agency

No.	Factor	Interview example	Interview
			code
S4	Agency	We figured out the written instructions	EG01
		you get many people who can't even read	EG01
		I did not take it at that time because I was hungry and tired	KN04
		[the dosage] would have been a bit of a guess	KZ01
		I was so tired	TZ02
		I didn't put it on my back very often because it was hard to get to	UK01
		I fill the containers for 7 days	UK02
		I got a little box with a week of separated compartments	UK06

Table 24: Interview content matched to S5, Availability of items in context

No.	Factor	Interview example	Interview code
S5	Context	The medicines here don't come with a spoon	EG01
		We cannot afford three meals a day so it was hard to take the tabs in the afternoon	KN04
		There was no body	KN07
		I lacked water for taking medicine	KN07
		I had eaten since the prescription required that	KN15
		Clean water	TZ02
		We are poor we can't afford most of the requirements.	UG01
		Sometimes we have a single meal a day	
		Took it with a drink	UK03

Table 25: Interview content matched to S6, A-C value assessment ex ante

No.	Factor	Interview example	Interview
			code
S6a	Norms	my husband was there, sometimes	EG01
		my mum she's basically telling me it's not good [to take medicine]	EG01
		Also, experience from other people	KN03
		stigma you are viewed in a different manner	KN04
		It's better for someone to make sure you get the full dose	KN06
		Grandmother was there with me	KN11
		Coming from a family where my grandparents would not allow me to take medicine	KZ01
		I try as much as possible to get it at home	NG01
		I never wanted to take that medicine because that I feared for stigma	TZ02
		My wife is the one who was always reminding me to take it	TZ03
		People should finish the dose as prescribed by the doctor	TZ03
		Someone else did it [for me]	UK01
		With the family	UK04
		Most of the time it was just me and [wife]	UK04
		[wife:] "Have you taken your tablets?"	UK05
S6b	Motivation	You realise it's hard for me [to wake at midnight]	KN03
		I knew that the disease is dangerous. If maybe I could	TZ02
		default then I could have been maybe in danger	
	Belief	this thing about the pharmaceutical industry and how they're making a profit	EG01
		Also because it's foreign	NG01
		Natural ones are better than synthetic	NG01
		Sometimes they say that the tablets are weak	TZ02
		I wouldn't like to be putting a lot of stuff into my body that I didn't know what it was doing	UK06
		I hear about these doctors saying about how conventional medications affect the liver	ZM01
	Agency	I felt desperate	KN08
		It took a while and was hard to put on	UK01
	Affordance	It's big and bitter	KN01
		the size of the pill the taste	KN03
		I hate the bitterness and largeness of tabs	KN04
		Some medicines are bitter	KN07
		tablets are in large sizes and so swallowing becomes a problem	KN08
		The size is too big and bitter	KN09
		Bitterness of the medicine	KN11
		Bitter	KN12
		Large to swallow and my throat is small	KN13
		They don't taste well when you swallow them	TZ03
	Context	I remember if I want to eat I have to take medicine	TZ03
		Getting up and going to bed. Part of the routine	UK01
		I remembered I had food so I could take it	UK01
		with my breakfast in the evening	UK02 UK03
		Took it with my breakfast every morning  A regular habit	UK03 UK03
		Tregular Habit	UNUS

Table 26: Interview content matched to S7, Value cocreation (P-C value)

No.	Factor	Interview example	Interview
S7	Motivation	I take it up to the last one	code KN05
5,	IVIOLIVALIOIT	Sometimes I take the medicine I feel like vomiting. But I continued	KN06
		You feel like not taking it	TZ01
		There didn't seem to be a lot of point	UK01
		Only because he said to take them I took them	UK04
		I was sad but I took it	UK05
	Belief	I could not actually imagine that there will be a prescription or directive on how to take [it]	KN07
		I'm just so grateful for getting the right treatment	UK06
		I took my pawpaws which I heard about on the radio and I was ok in 2 days	ZM01
		I went to the clinic I took some lemonade	ZM01
	Agency	it was my first time to use the medicine and so I did not know how to take it	KN08
		My teacher told me to follow the doctor's prescription	KN11
		Take 2 tablets 3 times in a day	KN05
		Two tablet after every six hours	KN11
		I don't find it easy	NG01
		I followed the instruction given to me by the doctor	TZ03
		I forgot to take it	TZ03
		Maybe you can miss in that case in the evening, or forget in the morning and then take in the afternoon and miss in	TZ04
		the evening, or someone can take 6 at once I was told how to take them	UK05
	Affordance	The prescription should say when the medicine should be	KN01
	Allordance	taken	
		medicines are difficult for me to take	KN04
		It is quite difficult for me to take them because of the smell but I sacrifice	KN05
		this medicine has a smell disturbs me a lot when taking this medicine	KN08
		I take it until I use all the tablets	NG01
		Took it strictly according to the prescription	TZ02
		Written on the doctor's prescription	UK03
		Some medicines smell nausea and vomiting	ZI01
	Context	[sufficient to stop you taking?] Yes!	KN03
	Context	when the time reaches to take the medicines you realise you have nothing to eat	KINUS
		I was occupied maybe from work I just forgot	TZ03
		If I was staying at someone's house I'd forget to take it	UK01
		When I unexpectedly stayed over at someone's house	UK01
		It was quite easy as long as I'd got them with me	UK03
		We had to eke them out instead of having like 2 tablets twice a day we have to have 1	UK04
	Norms	"today's a party"	KZ01
		I'm quite happy to take whatever he has prescribed	UK02
		I just do as I'm asked to do	UK06

Table 27: Interview content matched to S8, A-C value assessment ex post

No.	Factor	Interview example	Interview
			code
S8	Motivation	the moment you start to feel better you stop taking them	KN03
		sometimes I stop when I'm feeling better	
		When they see they're little better they stop taking the	NG01
		tabs	T704
		Since I knew the effect of drug pills, I just had to take it	TZ01
		you become very tired it is difficult [to] finish the dose	TZ02
		I stopped [taking when better]	TZ04
		They take long to heal, it's a long dosage I bought a large jar of Candarel and of course I stopped	TZ04 UG01
		making cake and eating it	UGUI
		The results were absolutely magical, marvellous, a	UK03
		miracle	UNUS
		I would not risk stopping taking them even though I've no	UK06
		swelling now	ONOO
		Not completing the full dosage caused by early signs of	ZI01
		healing	2101
	Belief	Sometimes it can harm your body	KN10
		it weakens my body for sometime	KN15
		Better to take herbs	NG01
		If I [stop] I could have maybe been in danger	TZ02
		I can go a fortnight without taking them. I'm not sure what	UK05
		I'm taking them for	
		I doubt his diagnosis	UK05
		I don't want to risk a return to the swelling and pain	UK06
	Agency	first two tablets of the day were regular and then not I	KZ01
		again collapsed	
		It said take 2 twice a day but I didn't know what that meant	UK01
		Not completing the full dosage caused by difficulty in	ZI01
		taking the medicine	
	Affordance	According to my experience, some medicine [makes you]	KN01
		develop boils, get sick, get weak, sweat a lot	
		I've had a [bad] taste after taking drugs, now vomit	KN03
		Some people are having problems in taking medicine	KN05
		I prefer short dose	KN06
		[preferred] through syringe	KN07
		I hate medicine they are bitter	KN09
		Large medicine are unfavourable for me	KN11
		I prefer the injection The medicine itself was reactive I was afraid of taking it	KN13 NG01
		Some medicines do emit a pungent smell	TZ02
		Sick for a whole week headaches, stomach stuff, the	ZI01
		pains. I thought not to go through all that	2101
		They feel like there's too many, and you swallow them	ZM01
		and it feels like you haven't and you wonder how you're	
		going to take the next tablets	
		I took one but couldn't take more because of the nasty	ZM01
		taste	-
	Context	I think I'm doing the NHS a service by not taking tablets	UK05
		Not completing the full dosage caused by lack of	ZI01
		monitoring of the sick by family members	
	Norms	Later on I realised that each and every person can get this	TZ02
		sick I [took] medicine openly	

	I don't want to have any problem coming up because I've decided not to take the medicine he's prescribed	UK02
	If I've got no pain then I don't need it preventing	UK05

These tables show that interview extracts are present for each of the factors putatively identified as being present in each of the subordinate propositions identified in Table 7.

This result aligns with and supports Qualitative Proposition 2. It can said with some confidence that the positioning and grouping of the adherence factors within the S-D Logic-derived initial process of adherence is reasonable.

It is now possible to visualise the initial process with this pattern of placement. Firstly, the factors in each grouping are displayed in Figure 25 below. Those which are patient-related are in red, with medicine-related factors in blue. Context is in black text. This figure shows how widespread is the patient's involvement in the process of adherence. While it shows a useful amount of detail, that amount may be too much for when rapid analysis in needed.

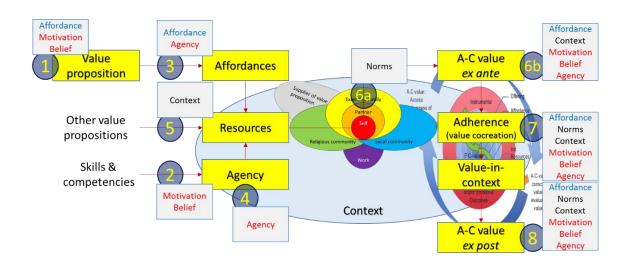


Figure 25: Initial process with groupings broken out

In order to make the figure more easily assimilable, it is possible to simplify it while still retaining its essential characteristics. This is the purpose of Figure 26. This will be referred to as the qualitative process of adherence. It retains the basic

underlying structure while removing the depictions of the Integrative Framework of Value and the service ecosystems since these are encapsulated in A-C value assessments and norms respectively. The unnecessary repetitions of agency and context are also removed, and norms has been moved to the *ex ante* A-C value assessment, not to take it out of context but to show that norms is important throughout the value assessment and value cocreation process.

The result of this work is a figure which is proposed to permit an enhanced understanding of the interactions that happen before, during and after the act of adherence. By this visualisation it is possible to see more clearly where each of the factors of adherence fits within the process and how the three constructs of patient, medicine and context come together to enable adherence.

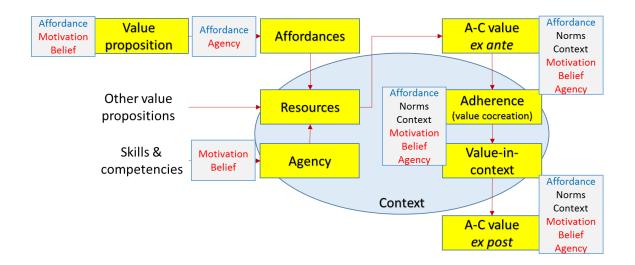


Figure 26: Qualitative process of adherence

Through this diagram it is made obvious the importance of the patient bringing all their resources with those of the medicine and the context in order to cocreate value, or to follow the process and so be adherent. This also indicates that many of the interactions both between patient and medicine as well as between medicine and context can be seen as a reaction to each other. By this is meant that, for example, a lack of affordance in the medicine may be made up by patient agency or context, or something lacking in the context could potentially be

addressed by the medicine or the patient. There are many examples of how these interactions might work out.

### 11.5 Summary

An initial discussion focused on descriptive details including interviewee demographics. This was followed by an analysis of the two Qualitative Propositions.

The two parts of Qualitative Proposition 1 looked at whether the interview data was comprehensive. Proposition 1a considered interview content bottom-up, categorising and then condensing categories until a taxonomy of adherence-related issues was created. This taxonomy demonstrated that all six factors of adherence identified from the literature and considered in Proposition 2 were indeed present in the interviews. This indicates that interviews and Proposition 1a are aligned.

Proposition 1b analysed the interview extracts to determine their coverage of the 55 causes of non-adherence. It found all but ten of the 55 were present in the interviews, and also uncovered 19 new causes not found in the 55 causes. This suggests that the interviews align with Proposition 1b. The alignment of interviews with both parts of Qualitative Proposition 1 increase confidence that Qualitative Proposition 2 is aligned with the interview data.

Moving to Proposition 2, eight subordinate propositions were created in support of its analysis. This analysis suggests that it is aligned with the interviews.

The visualisation of how the factors of adherence can be positioned within the S-D Logic-derived process, and how patient, medicine and context can be seen in the process, led to the creation of the qualitative process of adherence.

### 12 Qualitative Research Conclusions

#### 12.1 Introduction

This chapter provides an overall summary of the research and results, and draws conclusions.

The structure of this chapter is as shown in Figure 27.

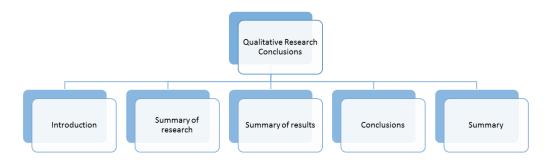


Figure 27: Chapter structure

### 12.2 Summary of research

A case-based approach was taken, commencing with qualitative research. Thirty semi-structured interviews were conducted over a period of about six months. Interviewees were deliberately selected to provide a wide range of experiences of medicine consumption in both developed and developing worlds. Interviews were transcribed and then analysed using Nivo10 and manual means.

The analysis was performed as an exploratory exercise to investigate two Qualitative Propositions, the first of which was in two parts. The second was to explore whether the placement onto the S-D Logic flow of the six adherence-related factors emerging from the literature was supported in reality rather than just theoretically.

The first proposition investigated the quality of the data emerging from the interviews in order to build confidence that Proposition 2 was well aligned with the interviews and so had good coverage of the six adherence factors. This was done in two ways. Firstly, the interview results were measured for their coverage

of the six adherence factors. Secondly, the results were processed to evaluate the extent to which they had uncovered the 55 causes of non-adherence.

## 12.3 Summary of results

Qualitative Proposition 1 was intended to give confidence in the quality of data coming out of the interviews. The means for so doing was to process the transcripts in two ways. The first was to find evidence for all six of the adherence factors by bottom-up analysis. This was achieved, showing an alignment with the Proposition. The second was to determine the extent of coverage of the 55 causes in the interviews. This work indicated that all but ten causes had been found – these being difficult to identify without face-to-face interviews where the interviewer is able to make personal assessments of the interviewees – and also discovered 19 new causes. This also suggests good alignment.

The interviews also aligned with Qualitative Proposition 2. This implies that it is indeed possible to position all six of the adherence factors appropriately onto the S-D Logic-derived initial view of the process. This gives confidence that the initial view is a reasonable depiction of the process of adherence, and has resulted in the creation of the qualitative process of adherence.

#### 12.4 Conclusions

It seems evident that the qualitative research results have indeed provided a rich view of adherence as part of people's lived lives in a range of environments from extreme poverty to relative comfort. The results of analyses for Proposition 1 indicate that the interviews were of sufficient quality to demonstrate alignment with Proposition 2.

The alignment of Proposition 2 gives confidence that end-to-end adherence on a per-opportunity level can be described by the qualitative process. This is a potentially significant step forwards in the understanding of the reasons for adherence and non-adherence which has not been achieved before using expectancy-value theories.

Based on the qualitative view of the process of adherence, it may be seen that some of the factors can actually be traded off against each other. For example, if the affordance of the medicine is perceived by the patient as being inadequate in itself to permit adherence to take place they may be able to call on other resources from norms, context and agency to overcome such inadequacy. If the medicine is bitter then the patient may be able to use their agency to bring sugar into context to sweeten it. If it requires food to be eaten at the point of consumption and there is none available then support may be obtained from an alternative service ecosystem. These simple examples demonstrate the potentially complex interactions between adherence factors.

What the qualitative research has not achieved is a detailed picture of those interactions between the six factors in the adherence process. It is possible that a more ethnographic approach to the qualitative research may have facilitated this. This was the purpose of the quantitative research. It was intended to identify moderating effects of the factors against each other. Such a step would require a drastically simplified model of interactions and therefore the removal from its S-D Logic base.

# **12.5 Summary**

In this chapter it has been shown that the Qualitative Propositions appear to align well with the initial process, and that the interview data is robust. This suggests that it is a good model for understanding adherence and so the qualitative process of adherence can be built on this.

The qualitative process was then tested quantitatively. The next chapter deconstructs the process in preparation for that quantitative work.

# 13 Developing a Quantitative Process of Adherence

#### 13.1 Introduction

This chapter takes the results of the qualitative research and simplifies the qualitative process to make it more suitable for testing quantitatively. The result is a quantitative process of adherence.

The structure of this chapter is as in Figure 28.



Figure 28: Chapter structure

### 13.2 Initial analysis

In support of the quantitative research it is now necessary to start from the qualitative process in which the adherence factors were placed in order to create a process which can be tested. This process will be referred to as the quantitative process of adherence.

The following points about adherence may be made from the qualitative process.

Firstly, the patient must have sufficient motivation and belief to put time, money and effort both into obtaining the medicine at the start of the process and bringing the required skills and competencies to bear to consume it.

Secondly, the affordance of the value proposition must be sufficient to provide the required resources into the consumption context.

Thirdly, the norms need to be favourable to consumption.

Fourthly, the A-C value *ex ante* assessment must indicate that, all things considered, consuming the medicine is the right thing to do.

Fifthly, at the point at which consumption takes place, all the required factors are positively aligned and remain so for the duration of the event.

Sixth and finally, although it does not affect consumption at the point of adherence, a favourable assessment must be made of the consumption event afterwards if further adherence is to be attempted. This *ex post* A-C value assessment may legitimately be made shortly after the adherence event or at a later time, depending on the time it takes for the effects of the medicine to be seen.

By deconstructing the qualitative view of the process of adherence it is possible to create a process which can be tested quantitatively.

### 13.3 Development of the process

Clearly, the starting point of the process of adherence is the patient while the endpoint is adherence. Without diminishing the importance of the medicine, it should be remembered that it is no more than an operand resource in the adherence context.

Considering the six points above it is possible to make the following observations based on the learning from the qualitative process.

Firstly, there are two sets of interacting factors: motivation, beliefs and agency one the one hand and affordance, norms and context on the other.

Secondly, if motivation and belief are sufficient for the patient to obtain the medicine and to bring agency to bear, then agency may become the factor affecting the patient's contribution to their adherence. If agency is adequate then the medicine's and the context's factors come into play. Affordance, norms and context could potentially each affect adherence. If they do not completely inhibit consumption then it may be assumed that consumption will occur and therefore that adherence will be achieved.

Therefore it is possible to see the three non-patient factors moderating the contributions of the three patient factors.

The Hypotheses for the quantitative research can now be presented.

**Hypothesis 1**: Patient-related factor motivation contributes to adherence

Hypothesis 2: Patient-related factor beliefs contributes to adherence

**Hypothesis 3**: Patient-related factor agency contributes to adherence

**Hypothesis 4**: The effect of patient-related factor motivation on adherence is moderated by affordance

**Hypothesis 5**: The effect of patient-related factor beliefs on adherence is moderated by affordance

**Hypothesis 6**: The effect of patient-related factor agency on adherence is moderated by affordance

**Hypothesis 7**: The effect of patient-related factor motivation on adherence is moderated by context

**Hypothesis 8**: The effect of patient-related factor beliefs on adherence is moderated by context

**Hypothesis 9**: The effect of patient-related factor agency on adherence is moderated by context

**Hypothesis 10**: The effect of patient-related factor motivation on adherence is moderated by norms

**Hypothesis 11**: The effect of patient-related factor beliefs on adherence is moderated by norms

**Hypothesis 12**: The effect of patient-related factor agency on adherence is moderated by norms.

This may be depicted as in Figure 29. This can form the basis for quantitative evaluation. In statistical terms each oval is a latent variable.

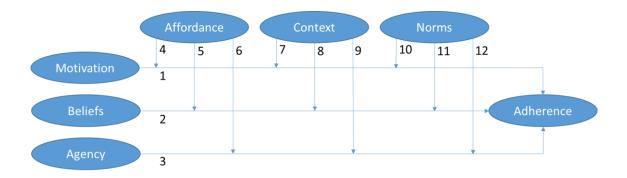


Figure 29: Quantitative process of adherence

This is clearly significantly simpler than even the S-D Logic-based qualitative process of adherence since none of the factors is placed into the multiple positions where they appear to have effects. As a result, this view of the process of adherence loses significant detail. Nevertheless it is a process which can be statistically tested.

## **13.4 Summary**

The qualitative process of adherence has been reviewed. This has been deconstructed and a quantitative process created in order to test it statistically.

Hypotheses 1-12 have been proposed.

It is now possible to move to the quantitative research. This is the first opportunity to test the quantitative process of adherence.

#### 14 Quantitative Research Method

#### 14.1 Introduction

This chapter describes the development and implementation of the quantitative research. The research was the first opportunity to evaluate the qualitative process of adherence quantitatively. The initial process emerging from the literature review aligned with the Qualitative Propositions, allowing a theoretical qualitative adherence process to be derived from it. However, the interview approach – mainly at a distance rather than ethnographic – was less successful in determining the interactions between the six factors. This understanding would provide more confidence that the qualitative process is valid for investigating adherence in future work, and also potentially identify survey instruments for the future. For these reasons quantitative research was performed. In the absence of statistically significant quantitative results it should be emphasised that the qualitative process of adherence stands alone, while it may be possible for the quantitative process of adherence to be explored in future research.

The structure of this chapter is shown in Figure 30.

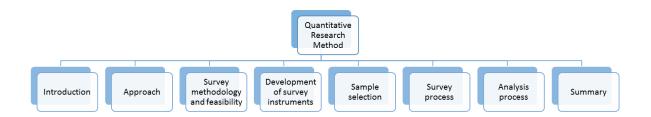


Figure 30: Chapter structure

## 14.2 Approach

The qualitative research consisted of semi-structured interviews to explore the Qualitative Propositions in an open-ended way. The results of these interviews aligned with the qualitative process of adherence. The opportunity was now taken to explore the interactions of the six factors in the qualitative process using a quantitative survey.

A survey was used as part of the mixed methods case in order to enhance triangulation, but to rely on this as the only research instrument would have restricted investigation to pre-determined questions rather than permitting the flexible approach to questioning that can be part of semi-structured interviews. Using a survey as an attempt to quantify the impacts of the various qualitative "insights, explanations, and meanings" (Yin 2013) on consumption permitted statistical analysis of the interactions between the six factors. The use of a cross-sectional survey, collecting data at a point in time, can make it possible to identify moderators of relationships between variables (Visser et al. 2000).

The approach to the design and execution of the survey followed the recommendations of Walonick (2013) and is shown in Figure 31.

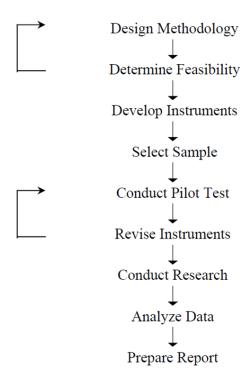


Figure 31: Survey design and execution process (Walonick 2013)

## 14.3 Survey methodology and feasibility

#### 14.3.1 Questionnaire

As previously indicated, the main purpose of this exploratory survey was to examine the potential interactions between the six adherence factors proposed by the quantitative process of adherence (Figure 29). To achieve this it was necessary to utilise survey instruments to investigate each of the seven latent variables. This implied a complex questionnaire design. In order to maximise the validity of the survey results while making the questionnaire as easy to complete as practicable, the following seven principles were implemented as recommended by Visser et al. (2000), Walonick (2013) and others.

Firstly, except for the initial questions about the medicine being reported on and the final demographic questions, all questions sought a response on a 7-point Likert scale. The 7-point scale has been shown to provide the highest levels of reliability and validity.

Secondly, the scale points were all labelled. This can improve data quality.

Thirdly, some questions had their scales inverted (reversed) in an attempt to prevent respondents answering without thought. These questions had their scale reinverted before analysis was performed. Table 43 (Appendix C.1) lists all questions, and notes with an asterisk those which were inverted.

Fourthly, questions were grouped by latent variable but then randomised within each group. This allows respondents to think about one latent variable at a time rather than have to move backwards and forwards between topics.

Fifthly, all questions were closed rather than open. This simplifies the analysis of survey answers. On their own, closed questions do not provide the opportunity to obtain the variety of input offered by open questions. However, by including in the questionnaire some questions derived directly from the qualitative interviews it was felt that this would maximise the range of information gathered. This would therefore contribute to the validity of the results.

Sixthly, and connected with the fifth, one method of improving face validity of the questionnaire is to consult with experts on the questions to be used (for example Rattray & Jones 2007; Hinkin et al. 1997). In this case, the qualitative interviewees were used as the experts. The reasons for non-adherence which they proffered were used either to enrich existing instruments or in some cases to replace them.

Seventh and finally, no questions were used which were obviously ambiguous, double-barrelled or contained a double negative.

### 14.3.2 Survey invitation and completion

There are several approaches to gathering survey data. These include: face-to-face or telephone interviews using structured questions; printed questionnaires; and computer or smartphone questionnaires. These are not mutually exclusive, and the use of several approaches may make it possible to reach a wider range of respondents.

The approach selected for this survey was primarily to deliver the survey online via a web browser or mobile phone, thus allowing respondents to use their computer or smartphone for their responses. This permitted data to be gathered and stored online and then later to be downloaded for analysis. Some responses were gathered through printed questionnaires, with the data entered into the online database so that all responses were held online.

Similarly, there are multiple non-exclusive ways of inviting participation. Postal mail, email, SMS messages, social media, newsletters, and word-of-mouth are just a few. There are indications that some modes of invitation can work more effectively than others in certain circumstances, for example email compared to SMS messages (De Bruijne & Wijnant 2014).

For this survey, the selected means of publicity were social media, newsletters, email and word-of-mouth. Relative effectiveness of the methods was not thought important since invitations were issued several times on social media in order to

both remind potential respondents who had already seen the invitation and to reach those who had not previously seen it.

### 14.4 Development of survey instruments

The purposes of developing the survey instruments were primarily to explore the relationships between the six adherence factors and secondly to identify possible instruments for use in future surveys.

This section considers each instrument in turn. Each instrument contributed to one latent variable or construct – the six factors plus adherence itself. They are presented alphabetically. Many potentially relevant existing survey instruments were explored and assessed before selecting the ones appropriate to the survey. In most cases the instrument was augmented with additional questions arising from the qualitative research in order to benefit from the insights gathered from them. These are labelled "Own" in the "Scale" column of the tables which follow. Ultimately a selection of the items was combined into a new survey instrument for each construct.

# 14.4.1 Adherence (consumption)

The most popular scale for measuring adherence was created by Morisky et al. and is known as the Morisky Medication Adherence Scale (MMAS) (Culig & Leppée 2014; Morisky et al. 1986). The 8-question version, MMAS-8, is preferred. The questions and the scoring are as in Table 28.

Although this scale has been used in surveys, it was primarily created for use in face-to-face discussions between patient and physician (Culig & Leppée 2014). It consists of several types of question which are treated as a single-dimension variable. Not surprisingly, papers have reported its validity measured by Cronbach alpha (Cronbach 1951) as being as low as 0.60 (for example Zongo et al. 2016).

Table 28: Questions and scoring for MMAS-8 (Morisky et al. 1986)

No.	Question
1	Do you sometimes forget to take your pills?
2	People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your medicine?
3	Have you ever cut back or stopped taking your medicine without telling your doctor because you felt worse when you took it?
4	When you travel or leave home, do you sometimes forget to bring along your medicine?
5	Did you take all your medicine yesterday?
6	When you feel like your symptoms are under control, do you sometimes stop taking your medicine?
7	Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?
8	How often do you have difficulty remembering to take all your medicine? A. Never/rarelyB. Once in a whileC. SometimesD. UsuallyE. All the time
	Scoring (number of questions answered "no")
0	High Adherence
1-2	Medium Adherence
3-8	Low Adherence

As well as its low alpha score, it is apparent that the MMAS-8 scale also only assesses a small subset of the very many reasons why patients may not be adherent. It looks at patient memory (3 questions), patient non-adherence due to feeling worse, patient non-adherence due to feeling better, and patient inconvenience. While it has proven to be valuable in clinical practice as a basis for face-to-face adherence interventions with patients (Culig & Leppée 2014), it is unsuitable for use in a survey which is aiming to understand reasons for non-adherence caused by a range of factors.

Instead, a set of four parallel questions was used to assess adherence as a latent variable, considering the basic level of consuming medicine. These questions were used simply to determine whether adherence was achieved. The other questions in the survey then addressed the reasons for non-adherence. Therefore, the questions used in the survey to represent adherence are listed in Table 29.

**Table 29: Adherence questions** 

No.	Scale	Question
1a	Own	I take my medicine according to the instructions
1b	Own	I take my medicine correctly
1c	Own	I take my medicine as prescribed
1d	Own	I take my medicine as I have been instructed

#### 14.4.2 Affordance

Affordances arise from the value proposition of the medicine. While in other spheres affordances might encourage consumption, the key consideration with medicine is that it and its packaging do not inhibit consumption.

There are some scales in the literature for product adoption which contain some relevant questions. For example, Flight et al. (2011) create 15 short scales relating to topics such as "Social compatibility", "Personal compatibility" and "Product performance". However, the 2-4 questions in each of these scales are at a very high level. For example, "Product performance" is examined using the following 3 questions:

- "1. This product will do what it claims it will do
- "2. This product will perform reliably and consistently
- "3. I am confident that this product will perform as expected".

Questions such as these do not explore the detail of the potential issues which have been uncovered in interviews. Therefore a set of questions was created by reference to insights from the qualitative research interviews (Table 30).

Table 30: Affordance questions from interviews

No.	Scale	Question		
1a	Own	There is nothing about the medicine itself which puts me off		
1b	Own	This medicine's features do not prevent me taking it		
1c	Own	The medicine itself gives me no problems taking it		
1d	Own	I have no problems taking the medicine itself		
2	Own	There is something about the medicine's taste that puts me off		
3	Own	There is something about the tablet size of this medicine that stops me taking it		
4	Own	There is something about the medicine's smell that stops me taking it		
5	Own	There is something about the form of this medicine that stops me taking it		
6	Own	There is something about the duration of course of treatment that stops me taking it		
7	Own	There is something about the medicine's packaging that stops me opening and taking it		
8	Own	I do not take my medicine because I know the bad side-effects it has had on others		
9	Own	I don't take this medicine because it is made by a profit-making company		
10	Own	I don't take this medicine because it contains unknown chemicals		

### **14.4.3 Agency**

Alkire (2005) defines agency as the "ability to act on behalf of goals that matter". He goes on to define agency as having four characteristics:

"...is part of one's own well-being (intrinsic value), can cause positive changes in some dimensions of one's well-being (instrumental value), can create further changes [which] one values (instrumental value), [and] may conflict with other dimensions of one's well-being".

The two "instrumental value" characteristics are very well aligned with taking medicine, while the fourth characteristic of "conflict" recognises that taking medicine may have short-term negative consequences.

Some scales claim to focus on self-efficacy but are more to do with motivation. For example, the MASES (Medication Adherence Self-Efficacy Scale) scale (Ogedegbe et al. 2003) includes "[How sure are you that you can take your... medicine all of the time] when you do not have symptoms" and "....when you do not like the taste". These questions do not reflect "ability to act" but motivation.

However the MUSE (Medication Understanding and Use Self-Efficacy) scale (Cameron et al. 2010) offers questions from the perspective of agency rather than

motivation and can be used in this survey. In addition, questions were developed from the qualitative interview and included in the instrument. Table 31 includes the MUSE questions and others developed from the interviews. These questions commence "It is easy for me to…", reflecting the focus of agency on the patient's ability to apply their skills and competences. However, "easy" may not be the appropriate definition and so this was changed to "I am able to…" in the survey.

While some of the MUSE questions may be considered less relevant than others, the same approach was taken as with other scales: all questions were included in the expectation that the unpromising questions would be shown to be so in the statistical analysis.

Table 31: Agency questions from MUSE (Cameron et al. 2010) and interviews

No.	Scale	Question		
1	MUSE	It is easy for me to take my medicine on time		
2	MUSE	It is easy for me to remember to take all my medicines		
3	MUSE	It is easy for me to set a schedule to take my medicines each day		
4	MUSE	It is easy for me to take my medicines every day		
5	MUSE	It is easy for me to ask my pharmacist questions about my medicine		
6	MUSE	It is easy for me to understand my pharmacist's instructions for my medicine		
7	MUSE	It is easy for me to understand instructions on medicine bottles		
8	MUSE	It is easy for me to get all the information I need about my medicine		
9	Own	It is easy for me to take my medicine without help		
10	Own	It is easy for me to know when to take my medicine		
11	Own	It is easy for me to understand why I should take my medicine		

#### **14.4.4 Beliefs**

Two scales were compared before settling on the one potentially most practical.

Firstly, the Beliefs about Medicines Questionnaire (BMQ) (Horne et al. 1999). This was derived from a consideration of theories such as the Theory of Planned Behaviour (Ajzen 1991; Ajzen 1985) plus empirical research. The resulting questionnaire contains questions in two sections labelled "BMQ-General" and "BMQ-Specific". The two lists are contained in Table 32. Each question is rated on a 5-item Likert scale ranging from strongly agree to strongly disagree.

Table 32: Beliefs about Medicines Questionnaire (BMQ) (Horne et al. 1999)

No.	BMQ-Specific	
1	My health, at present, depends on my medicines	
2	Having to take medicines worries me	
3	My life would be impossible without my medicines	
4	Without my medicines I would be very ill	
5	I sometimes worry about long-term effects of my medicines	
6	My medicines are a mystery to me	
7	My health in the future will depends [sic] on my medicines	
8	My medicines disrupt my life	
9	I sometimes worry about becoming too dependent on my medicines	
10	My medicines protect me from becoming worse	
	BMQ-General	
1	Doctors use too many medicines	
2	People who take medicines should stop their treatment for a while every now and again	
3	Most medicines are addictive	
4	Natural remedies are safer than medicines	
5	Medicines do more harm than good	
6	All medicines are poisons	
7	Doctors place too much trust on medicines	
8	If doctors had more time with patients they would prescribe fewer medicines	

These questions cover a range of beliefs and are stated with varying levels of definiteness. For example, responding "strongly agree" to questions starting with "I sometimes worry..." and "Most medicines..." has a different level of force to responding in the same way to "My health depends on..." or "My life would be impossible without...". Even though internal consistency and discriminant validity were reported by its creators as being satisfactory, their robustness is questionable in this research context. This instrument was therefore passed over.

Secondly, the Drug Attitude Inventory (DAI). This was created by Kane et al. (2008). The DAI-30 scale consists of 30 questions aiming to understand attitudes towards medicine. Attitudes and beliefs are considered to be synonymous in this context. This instrument was selected (Table 33).

Although some of the questions may not precisely relate to *ex ante* beliefs and the instrument as a whole is too long, all questions were retained and it was augmented by outputs from the qualitative interviews in the expectation that subsequent statistical analysis would resolve the issue. The full list is in Table 33. In the survey the DAI-30 questions were reworded to focus on the particular

medicine under consideration, while to make it explicit that they are to do with beliefs about the medicine they were prefixed with "I believe [that]...".

Four of the beliefs questions relate to norms rather than beliefs. These are in italics in Table 33 and were separated out to form the norms instrument when processing the results.

Table 33: Belief questions from DAI-30 (Kane et al. 2008) and interviews

	Scale	Question		
1	DAI-30	I don't need to take medication once I feel better		
2	DAI-30	For me, the good things about medication outweigh the bad		
3	DAI-30	I feel strange, "doped up", on medication		
4	DAI-30	Even when I am not in hospital I need medication regularly		
5	DAI-30	If I take medication, it's only because of pressure from other people		
6	DAI-30	I am more aware of what I am doing, of what is going on around me, when I		
		am on medication		
7	DAI-30	Taking medications will do me no harm		
8	DAI-30	I take medications of my own free choice		
9	DAI-30	Medications make me feel more relaxed		
10	DAI-30	I am no different on or off medication		
11	DAI-30	The unpleasant effects of medication are always present		
12	DAI-30	Medication makes me feel tired and sluggish		
13	DAI-30	I take medication only when I feel ill		
14	DAI-30	Medications are slow-acting poisons		
15	DAI-30	I get along better with people when I am on medication		
16	DAI-30	I can't concentrate on anything when I am taking medication		
17	DAI-30	I know better than the doctors when to stop taking medication		
18	DAI-30	I feel more normal on medication		
19	DAI-30	I would rather be ill than taking medication		
20	DAI-30	It is unnatural for my mind and body to be controlled by medications		
21	DAI-30	My thoughts are clearer on medication		
22	DAI-30	I should keep taking medication even if I feel well		
23	DAI-30	Taking medication will prevent me from having a breakdown		
24	DAI-30	It is up to the doctor to decide when I should stop taking medication		
25	DAI-30	Things that I could do easily are much more difficult when I am on medication		
26	DAI-30	I am happier and feel better when I am taking medications		
27	DAI-30	I am given medication to control behaviour that other people (not myself) don't		
		like		
28	DAI-30	I can't relax on medication		
29	DAI-30	I am in better control of myself when taking medication		
30	DAI-30	By staying on medications I can prevent myself getting sick		
31	Own	I have to take this medicine because my religious faith has not cured me		
32	Own	It is not good to be seen taking this medicine		
33	Own	Natural remedies are safer for me to take than this medicine		
34	Own	I am getting better because of taking this medicine		
35	Own	I can get better in other ways than taking this medicine		

#### **14.4.5 Context**

S-D Logic shows that the value proposition of the medicine only permits value cocreation when appropriate additional value propositions are also present. These might include water, food, containers, or even appropriate assistance. Adherence studies tend to assume that these are generally available, since a developed-world mindset would never anticipate them to be missing. This can mean that processes by which they come into context may be overlooked in such studies. However, it is clear from qualitative interviews that this assumption is not always valid and that context questions should be included in the survey. These questions were generated from interviews and are listed in Table 34. In the survey these questions were prefixed with "In my situation..." to emphasise the question was about context and not the medicine itself (affordance) or the patient's capabilities (agency).

Table 34: Context questions from interviews

No.	Scale	Question	
1a	Own	I have everything I need to take my medicine	
1b	Own	There is nothing missing at the time I need to take my medicine	
1c	Own	When the time comes to take my medicine I have all the things I need	
1d	Own	I have everything available to me to allow me to take my medicine	
2	Own	At the time I take my medicine I have the food I need to allow me to do so	
3	Own	At the time I take my medicine I have the water I need to allow me to do so	
4	Own	At the time I take my medicine I have the utensils (spoon, syringe, etc) I need to	
		allow me to do so	
5	Own	At the time I take my medicine I have the help I need to allow me to do so	
6	Own	At the time I take my medicine I have the containers (cup, measuring jug, etc) I	
		need to allow me to do so	
7	Own	I do not take my medicine because of the stigma attached to it or to my illness	

### 14.4.6 Motivation

Ryan & Deci (2000) state that motivation may be both intrinsic ("for its inherent satisfactions") and extrinsic ("in order to attain some separable outcome"). They define four dimensions of motivation: "external regulation", "introjection", "identification" and "integration". As it has been indicated earlier, there may be occasions when medicine is consumed for its intrinsic "inherent satisfactions" but

this is likely to be an unusual event. The focus is therefore on the four dimensions of extrinsic motivation as listed in Table 35.

Each of these can be assessed with appropriate questions. A comprehensive approach to looking at each of these dimensions can be found in a paper by Pelletier et al. (1997). It assesses motivation for therapy using what the authors refer to as the "Client Motivation for Therapy Scale" (CMOTS). The authors found their questions for each dimension to be internally consistent and with good construct validity, while the results when moving up from "external" to "integrated" were positively correlated with increasing effectiveness of (and by implication adherence to) therapy. Therefore the more a respondent's "centre of gravity" of answers lie in the higher dimensions, the more motivated they are. This is valuable for assessing a respondent's motivation for being adherent to medicine prescriptions.

Table 35: The four levels of extrinsic motivation (Ryan & Deci 2000)

Level of extrinsic motivation	Definition		
External	"to satisfy an external demand externally regulated"		
Introjected	"feeling of pressure in order to avoid guilt or anxiety"		
Identification	"identified with the personal importance of a behaviour accepted its		
	regulation as his or her own"		
Integrated	"when identified regulations have been fully assimilated into		
	congruence with one's other values and needs"		

Although there are many questions in this instrument, the same approach was taken and all questions retained. Some minor wording adjustments were made such that they focused on medicine rather than therapy. The original CMOTS questions are in Table 36, and were reworded to refer to medicine for the survey.

Table 36: Motivation questions from CMOTS (Pelletier et al. 1997)

Dimension	Question			
External	Because other people think that it's a good idea for me to be in therapy			
	Because my friends think I should be in therapy			
	Because I don't want to upset people close to me who want me to be in therapy			
	To satisfy people close to me who want me to get help for my current situati			
Introjected	Because I would feel guilty if I were not doing anything about my problem			
	Because I would feel bad about myself if I didn't continue my therapy			
	Because I should have a better understanding of myself			
	Because it is important for clients to remain in therapy until it's finished			
Identification	Because I would like to make changes to my current situation			
	Because I believe that eventually it will allow me to feel better			
	Because I believe that therapy will allow me to deal with things better			
	Because I believe it's a good thing to do to find solutions to my problem			
Integrated	Because through therapy I've come to see a way that I can continue to approach different aspects of my life			
	Because through therapy I feel that I can now take responsibility for make			
	changes in my life			
	Because I feel that changes that are taking place through therapy are			
	becoming part of me			
	Because I value the way therapy allows me to make changes in my life			

#### 14.4.7 Norms

As noted in the section above, some of the beliefs questions relate to norms. The norms questions in the belief table are extracted and repeated here in Table 37 together with the numbering from that table for ease of reference.

Table 37: Norms questions extracted from the list in the beliefs table

No.	Scale	Question	
5	DAI-30	If I take medication, it's only because of pressure from other people	
27	DAI-30	I am given medication to control behaviour that other people (not myself) don't	
		like	
31	Own	I have to take this medicine because my religious faith has not cured me	
32	Own	It is not good to be seen taking this medicine	

# 14.4.8 Finalising the questionnaire

As a result of the preceding subsections it was possible to finalise the list of survey questions. These are listed in Table 43 (Appendix C.1). It will be seen that there were approximately 100 questions. This is considered to be an acceptable length for survey methods such as paper-based questionnaires, but may be too

long for use online where surveys should take no longer than 15 minutes (de Leeuw et al. 2008).

# 14.5 Sample selection

Inappropriate respondent selection is a potential source of bias in a survey. There are two general approaches to selection: probability and non-probability (Visser et al. 2000).

Probability sampling refers to random selection of respondents using methods such as simple, systematic, stratified and cluster. All such methods are susceptible to sampling errors when the sampled population does not fully reflect the nature of the overall population. The greater the divergence, the larger the coverage error. However, these methods are more likely to achieve a representative sample of the population than non-probability samples.

Non-probability sampling refers to selection of respondents using methods such as haphazard (convenience), snowball, purposive, and quota. The limitations of such methods are recognised in the warnings which are voiced about drawing conclusions about a population on the basis of likely non-representative samples (de Leeuw et al. 2008; Visser et al. 2000).

Respondents were recruited via a combination of methods. The main method was via the social media of Facebook, Twitter and WeChat. Other methods included a departmental postgraduate newsletter. Some respondents invited their friends and family to participate. While this may have achieved some probability sampling, the majority was likely to have been convenience and snowball sampling.

# 14.6 Survey process

The survey was presented online using Qualtrics (<u>warwickwmg.eu.qualtrics.com</u>) software. This is the preferred survey tool for the WMG department of the University of Warwick. However, coverage errors are hard to assess with online

surveys, meaning that there is uncertainty over whether respondents can ever be representative of the population.

All those surveyed confirmed their willingness to participate as they commenced the survey.

#### 14.6.1 Pilot test and instrument revision

The pilot test provides the opportunity to assess the survey before it is launched. There are essentially two non-exclusive ways to achieve this. Each uses a small number of respondents recruited for the task.

The first is simply to obtain feedback. This is sometimes called the conventional approach (Visser et al. 2000). Questions which are problematic, such as being badly worded, confusing, or with a high rate of non-response, can be corrected or removed.

The second is to analyse the results statistically. It is recommended that the same approach to statistical analysis be applied to the pilot results as will be used for the final results (Rattray & Jones 2007). This permits analysis of internal and external validity, Cronbach alpha assessment for each latent variable, Principal Component analysis, and so on. By these means, and applied iteratively where appropriate, the items for each construct are refined until only those which significantly represent each construct remain.

A validation version of the survey requesting feedback was publicised using Facebook and personal emails, and 19 respondents completed the survey. The first approach was taken, and feedback from the pilot led to minor wording changes to two questions.

#### 14.6.2 Full survey

The final version was publicised through Facebook, Twitter, WeChat, University of Warwick newsletters and postgraduate communications. Several follow-up communications were sent out to prompt greater participation.

Data collection ran for a period of approximately four months, with responses recorded from 1<sup>st</sup> July to 26<sup>th</sup> October 2016.

### 14.7 Analysis process

Each of the latent variables was defined by the set or a subset of survey questions (items) making up an instrument. As can be seen from Table 43 in Appendix C.1, each question was given a variable name and a number.

As a result of the qualitative research determining that developing and developed world adherence issues were substantially similar, answers from the both worlds were processed together.

All questions with inverted Likert scales had their answers re-inverted before analysis. The software package Stata v14 was used for the analysis.

Processing was as follows.

Step 1. The responses were downloaded from the Qualtrics survey management tool. The data was then cleansed to remove all responses where there were missing answers to questions. This was so that no data had to be interpolated by Stata v14 to infill missing answers. This left only fully completed responses.

Step 2. Questions which were coded on an inverted Likert scale were re-inverted. A descriptive analysis was then performed for each instrument using the *summarize* command.

Step 3. Items were selected which best represented each instrument in order to create a latent variable from them. The *factor* command was used on each instrument in turn, with the options *pcf* and *factors(1)* to obtain one Principal Component. Because only one factor was selected there was no need to check for discriminant validity. Then the *rotate* command was used for each instrument, with the option *orthogonal* on the assumption that factors were not correlated. This was done in order to identify the items which most strongly contributed to the first Principal Component. The same commands were then used iteratively on the items selected, eliminating those not contributing strongly, until there was

a group of items each with a contribution to the first factor of more than 0.7. This figure shows that the items demonstrated acceptable convergent validity. The proportion contribution of each to that Principal Component was then captured. The *alpha* command was then run against these items to determine the reliability of the scale. Finally, a latent variable was created from the selected items of each instrument by using the *generate* command to create the mean of the item scores.

Step 4. A correlation analysis for the seven latent variables was performed using the *pwcorr* pairwise correlation command with options *obs* and *sig*. This was to discover whether there were any statistically significant correlations between them. A correlation matrix was created from this result.

Step 5. A moderation analysis was performed. The three medicine and context variables were tested for their moderating effects on the three patient-representing latent variables. These tests align with the latent variables in Figure 29 and represent hypotheses 4-12. If moderating effects were present then the interaction term would be significant. Through these tests, evaluation of the hypotheses 1-3 was included since if there were low or no moderating effects then the direct effect would be shown if the direct relationship were to be significant; however, it could be argued that even though there was a lack of significant relationships there was perhaps some evidence of a contribution.

# **14.8 Summary**

The quantitative survey was a first step towards testing the qualitative process of adherence (Figure 26) through its deconstruction into the quantitative process (Figure 29), and also for investigating potential new instruments for measuring factors affecting adherence. The questions in the survey were primarily derived from existing survey instruments with the addition of questions created from answers provided in the qualitative interviews. Recommended processes were followed for design, development, validation, production and analysis of the survey. In particular, a careful step-by-step procedure was followed for statistical analysis.

# 15 Quantitative Research Results and Analysis

#### 15.1 Introduction

This chapter covers the results and analysis of the quantitative survey. Results begin with the selection of items for each latent variable then proceed with a correlation matrix of those variables. Moderation analysis then follows.

The structure of this chapter is as in Figure 32.

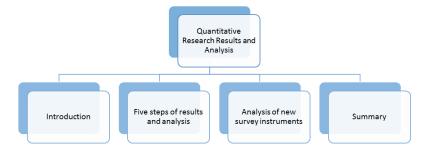


Figure 32: Chapter structure

## 15.2 Five steps of results and analysis

This section records the results obtained from the quantitative research and analyses them. The process that was followed is documented in the previous chapter.

# 15.2.1 Step 1: Download and initial analysis

Survey data was downloaded from the Qualtrics survey management tool into a spreadsheet. A total of 192 surveys was recorded.

Upon investigation it was discovered that the majority of respondents had commenced the survey but had not completed it. Some had stopped towards the end but many had stopped much earlier.

Removing the incomplete responses resulted in a total of 49 valid respondents.

### 15.2.2 Step 2: Descriptive analysis for each instrument

Each question in Table 43 in Appendix C.1 which is noted as "inverted" was reinverted such that the high score indicated the best result for adherence. For example, question "Belief35" makes the statement, "I believe that I can get better in other ways than taking this medicine" with a range of "Strongly Disagree" (1) to "Strongly Agree" (7). However, so that higher scores gave most positive results for adherence, the scores were re-inverted so that it effectively was rated from "Strongly Agree" (1) to "Strongly Disagree" (7).

The results of the *summarize* commands for each instrument are recorded in Appendix C.2.

One notable feature of the results is that almost every question shows a range of scores from 1 to 7. This results in high standard deviations. The reason for this is hard to determine. It may be because the wide range of views represents a wideranging experience of medicine consumption. It is also possible that it originates from a failure to understand the questions or a lack of interest in the survey leading to multiple selections of the same score for multiple questions. There is some evidence of the latter.

### 15.2.3 Step 3: Selection of representative items

This process iterated the *factor* and *rotate* commands, then calculated the level of convergent validity with Cronbach's alpha by using the *alpha* command. Only the first Principal Component was extracted because of the lack of valid responses.

The results of the final iteration are shown in each figure in this section, together with Cronbach's alpha coefficient. The section provides a table summarising the information. Details for each latent variable follow.

Suitable statistical processes were applied to analysing the data. However it should be noted that, since the number of completed survey responses was inadequate for statistically valid results to be obtained, no conclusions can be drawn from the quantitative research. As part of this it should be recognised that the extraction of items satisfactorily loading the first Principal Component is not statistically supported.

The Adhere(nce) latent variable reflects respondents' level of adherence to instructions. Four items made up this instrument.

All four Adhere items loaded factor 1 at 0.7 or above. They were all taken as the first Principal Component representing adherence. Cronbach's alpha was good at 0.76. The proportion of variance explained was 0.58.

- . factor Adherela Adherelb Adherelc Adhereld, pcf factors(1)
- . rotate, orthogonal

Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 4

Factor | Variance Difference Proportion Cumulative
Factor1 | 2.33651 . 0.5841 0.5841

LR test: independent vs. saturated: chi2(6) = 51.45 Prob>chi2 = 0.0000

Rotated factor loadings (pattern matrix) and unique variances

Variable	Factor1	Uniqueness
Adherela	0.7003	0.5096
Adherelb	0.7904	0.3752
Adherelc	0.7866	0.3812
Adhereld	0.7762	0.3975

#### . alpha Adherela Adherelb Adherelc Adhereld

Test scale = mean(unstandardized items)

Average interitem covariance: .6570295 Number of items in the scale: 4 Scale reliability coefficient: 0.7587

Figure 33: Final selection of items for Adhere(nce) latent variable

The Aff(ordance) latent variable reflects the qualities which the medicine brings to the consumption context.

Five out of the 13 Aff items loaded factor 1 at 0.7 or above. These were taken as the first Principal Component representing affordance. Cronbach's alpha was high at 0.87. The proportion of variance explained was 0.66.

The items which load the Principal Component most strongly form a logical group of the questions. Aff1c is to do with problems taking medicine. Aff2, Aff3, Aff4 and Aff5 relate directly to reasons why the medicine is not easy to consume. Therefore the first Principal Component represents this.

- . factor Aff1c Aff2 Aff3 Aff4 Aff5, pcf factors(1)
- . rotate, orthogonal

```
Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 5

Factor | Variance Difference Proportion Cumulative
Factor1 | 3.31572 . 0.6631 0.6631

LR test: independent vs. saturated: chi2(10) = 123.29 Prob>chi2 = 0.0000
```

Rotated factor loadings (pattern matrix) and unique variances

Variabl	e   Factor1	Uniqueness
Aff1 Aff7 Aff Aff7 Aff	2   0.8116 3   0.8406 4   0.8343	0.4840 0.3413 0.2933 0.3039 0.2618

. alpha Aff1c Aff2 Aff3 Aff4 Aff5

Test scale = mean(unstandardized items)

Average interitem covariance: 2.029365 Number of items in the scale: 5 Scale reliability coefficient: 0.8710

Figure 34: Final selection of items for Aff(ordance) latent variable

The Agency latent variable explains the patient's resources which they bring to consuming the medicine.

Four out of the 11 Agency items loaded factor 1 at 0.7 or above. These were taken as the first Principal Component representing agency. Cronbach's alpha was good at 0.79. The proportion of variance explained was 0.61.

The four items are aligned in the Agency items. They all relate to respondents' ability to consume their medicine at the right time in the right way.

- . factor Agency1 Agency2 Agency8 Agency10, pcf factors(1)
- . rotate, orthogonal

```
Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 4

Factor | Variance Difference Proportion Cumulative
Factor1 | 2.44275 . 0.6107 0.6107

LR test: independent vs. saturated: chi2(6) = 55.17 Prob>chi2 = 0.0000
```

Rotated factor loadings (pattern matrix) and unique variances

Variable	Factor1	Uniqueness
Agency1	0.8630	0.2552
Agency2	0.7508	0.4362
Agency8	0.7589	0.4241
Agency10	0.7472	0.4417

#### . alpha Agency1 Agency2 Agency8 Agency10

Test scale = mean(unstandardized items)

Average interitem covariance: 1.21875 Number of items in the scale: 4 Scale reliability coefficient: 0.7859

Figure 35: Final selection of items for Agency latent variable

The Belief latent variable relates to the patient's beliefs about themselves and their medicines.

Four out of the 31 Belief items loaded factor 1 at 0.7 or above. These were taken as the first Principal Component representing belief. Cronbach's alpha was good at 0.78. The proportion of variance explained was 0.61.

These four items form a group which refer to qualities of the medicine. These beliefs are therefore directly related to the decision on whether to consume the medicine.

- . factor Belief3 Belief14 Belief25 Belief28, pcf factors(1)
- . rotate, orthogonal

```
Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 4

Factor | Variance Difference Proportion Cumulative

Factor1 | 2.42067 . 0.6052 0.6052

LR test: independent vs. saturated: chi2(6) = 51.52 Prob>chi2 = 0.0000
```

Rotated factor loadings (pattern matrix) and unique variances

Variable   Factor1   Uniqueness  Belief3   0.8081   0.3469 Belief14   0.7565   0.4276 Belief25   0.7837   0.3858 Belief28   0.7622   0.4190			
Belief14   0.7565   0.4276 Belief25   0.7837   0.3858	Variable	Factor1	Uniqueness
	Belief14   Belief25	0.7565   0.7837	0.4276 0.3858

#### . alpha Belief3 Belief14 Belief25 Belief28

Test scale = mean(unstandardized items)

Average interitem covariance: 1.789966 Number of items in the scale: 4 Scale reliability coefficient: 0.7817

Figure 36: Final selection of items for Belief latent variable

The Con(text) variable is to do with the context in which the patient consumes their medicine.

Four out of the ten Con items loaded factor 1 at around 0.7 or above. These were taken as the first Principal Component representing context. Cronbach's alpha was good at 0.78. The proportion of variance explained was 0.61.

The items selected relate directly to the patient having the contextual resources required to consume their medicine.

- . factor Con1c Con1d Con2 Con3, pcf factor(1)
- . rotate, orthogonal

```
Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 4

Factor | Variance Difference Proportion Cumulative
Factor1 | 2.42453 . 0.6061 0.6061

LR test: independent vs. saturated: chi2(6) = 54.13 Prob>chi2 = 0.0000
```

Rotated factor loadings (pattern matrix) and unique variances

Variable	Factor1	Uniqueness
Con1c	0.6913	0.5221
Con1d	0.8673	0.2478
Con2	0.7411	0.4508
Con3	0.8032	0.3548

. alpha Con1c Con1d Con2 Con3

Test scale = mean(unstandardized items)

Average interitem covariance: 1.767432 Number of items in the scale: 4 Scale reliability coefficient: 0.7754

Figure 37: Final selection of items for Con(text) latent variable

The Mot(ivation) variable relates to the patient's motivation to consume the medicine.

Four out of the 16 Mot items loaded factor 1 at 0.7 or above. These were taken as the first Principal Component representing motivation. Cronbach's alpha was high at 0.81. The proportion of variance explained was 0.64.

This group of four items reflect a strong level of motivation since they are very high up the scale at the "Identification" (one question) and "Integrated" (three questions) levels (see Table 35). This is therefore a sensible grouping of items into a latent variable.

- . factor Mot11 Mot13 Mot15 Mot16, pcf factors(1)
- . rotate, orthogonal

```
Factor analysis/correlation Number of obs = 49
Method: principal-component factors Retained factors = 1
Rotation: orthogonal varimax (Kaiser off) Number of params = 4

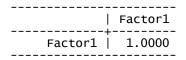
Factor | Variance Difference Proportion Cumulative
Factor1 | 2.56899 . 0.6422 0.6422

LR test: independent vs. saturated: chi2(6) = 65.92 Prob>chi2 = 0.0000
```

Rotated factor loadings (pattern matrix) and unique variances

Vari	able	Factor1	Uniqueness
M M	ot11   ot13   ot15   ot16	0.7229 0.8009 0.8644 0.8111	0.4775 0.3585 0.2529 0.3422

Factor rotation matrix



. alpha Mot11 Mot13 Mot15 Mot16

Test scale = mean(unstandardized items)

Average interitem covariance: 2.648597 Number of items in the scale: 4 Scale reliability coefficient: 0.8103

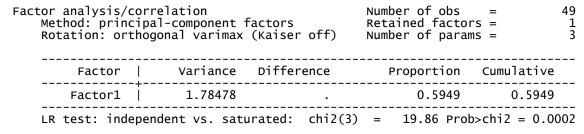
Figure 38: Final selection of items for Mot(ivation) latent variable

Norms relates to the service ecosystems in which the patient is located, and the rules and support obtained from them.

Three out of the four Norm items loaded factor 1 at 0.7 or above. These were taken as the first Principal Component representing norms. Cronbach's alpha was low at 0.65 but this is a new instrument. The proportion of variance explained was 0.60.

This group of three items reflect a coherent view of norms which clearly relate to others' perception of the patient.

- . factor Belief5 Belief31 Belief32, pcf factors(1)
- . rotate, orthogonal



Rotated factor loadings (pattern matrix) and unique variances

Variable	Factor1	Uniqueness
Belief5	0.7932	0.3709
Belief31	0.7511	0.4359
Belief32	0.7691	0.4084

#### . alpha Belief5 Belief31 Belief32

Test scale = mean(unstandardized items)

Average interitem covariance: 1.056548
Number of items in the scale: 3
Scale reliability coefficient: 0.6520

Figure 39: Final selection of items for Norm latent variable

Based on the latent variable creation process above, it is now possible to display them in tabular form.

**Table 38: Table of latent variables** 

Latent variable	Question	Factor loading	Variance explained	Cronbach's alpha		
Adhere(nce)	Adhere1a	0.70	0.58	0.76		
/ tariore(noc)	Adhere1b	0.79	0.00	0.70		
	Adhere1c	0.79				
	Adhere1c	0.78				
Aff(ordance)	Aff1c	0.72	0.66	0.87		
/ (ii (ordanoc)	Aff2	0.81	0.00	0.07		
	Aff3	0.84				
	Aff4	0.83				
	Aff5	0.86				
Agency	Agency1	0.86	0.61	0.79		
l igono,	Agency2	0.75				
	Agency8	0.76				
	Agency10	0.75				
Belief	Belief3	0.81	0.61	0.78		
	Belief14	0.76				
	Belief25	0.78				
	Belief28	0.76				
Con(text)	Con1c	0.69	0.61	0.78		
	Con1d	0.87				
	Con2	0.74				
	Con3	0.80				
Mot(ivation)	Mot11	0.72	0.64	0.81		
, ,	Mot13	0.80				
	Mot15	0.86				
	Mot16	0.81				
Norm	Belief5	0.79	0.60	0.65		
	Belief31	0.75				
	Belief32	0.77				

### 15.2.4 Step 4: Principal Component correlation matrix

The next step in statistical analysis was to create a correlation matrix of the eight first-level latent variables. This is shown in Figure 40.

. pwcorr Adhere Aff Agency Belief Con No	orm Mot.	aency Belief Con Norm Moi	obs sia
--	----------	---------------------------	---------

	Adhere	Aff	Agency	Belief	Con	Norm	Mot
Adhere	1.0000						
	49						
Aff	0.2093	1.0000					
	0.1490 49	49					
Agency	0.4944	0.4413	1.0000				
	0.0003 49	<b>0.0015</b> 49	49				
Belief	   -0.0665   0.6497	-0.1070 0.4641	-0.1347	1.0000			
	49	49	0.3561 49	49			
Con	0.1165	0.2452	0.4299	-0.3233	1.0000		
	0.4254   49	0.0895 49	<b>0.0021</b> 49	<b>0.0235</b> 49	49		
Norm	-0.0798	-0.1610	-0.0070	0.4585	-0.1688	1.0000	
	0.5859   49	0.2692 49	0.9617 49	<b>0.0009</b> 49	0.2463 49	49	
Mot	0.0102	0.0375	0.0423	-0.0813	-0.0003	-0.1063	1.0000
	0.9448   49	0.7979 49	0.7730 49	0.5785 49	0.9984 49	0.4674 49	49

Figure 40: Correlation matrix for the seven first-level latent variables

This matrix shows statistically significant correlations between Adhere(nce) and Agency, between Aff(ordance) and Agency, between Norm and Belief, between Con(text) and Agency, and between Con(text) and Belief. These are highlighted in bold text. However, it must be reiterated that any such relationship is not statistically supported and is therefore likely to be spurious.

Although no correlations are strong, any greater than 0.3 may indicate a possible regression result. However, the lack of a statistically significant relationship between latent variables does not necessarily mean that those variables are not involved in any relationships. There may be moderating relationship in which they play a part. This was examined next.

### 15.2.5 Step 5: Moderation analysis

This step tested for any moderating effects of the three non-patient variables on the three patient variables. The interaction term was in each case created by multiplying together the independent and putative moderation terms.

In summary, there were no statistically significant moderating effects between any of the moderating variables and the relationship of the independent variables to Adhere(nce). This means that none of the hypotheses 4-12 were found to be supported. In addition, there were no significant relationships found between the independent variables and Adhere(nce). This means that none of the hypotheses 1-3 were found to be supported.

#### . regress Adhere Aff Mot AffXMot

Source	SS	df	MS		er of obs	=	49 0.97
Model Residual	2.51425967 39.0520669	3 45	.838086555 .867823708	Prob R-sc	) > F  uared  R-squared	=	0.4172 0.0605 -0.0021
Total	41.5663265	48	.865965136	Root	: MSE	=	.93157
Adhere	Coef.	Std. Err.	t	P> t	[95% C	onf.	Interval]
Aff Mot AffXMot _cons	031653 1891048 .038963 6.095623	.1912674 .225437 .0435711 .9748666		0.869 0.406 0.376 0.000	41688 64315 04879 4.1321	82 38	.3535793 .2649485 .1267198 8.059106

Figure 41: Regression of Aff(ordance) on Mot(ivation)

#### . regress Adhere Aff Belief AffXBelief

Source	SS	df	MS		per of obs . 45)	=	49 1.93
Model Residual	4.73152456 36.834802	3 45	1.5771748! .81855115!	5 Prol 5 R-s	y +3) > F quared R-squared	=	0.1388
Total	41.5663265	48	.865965136		t MSE	=	.90474
Adhere	Coef.	Std. Err.	t	P> t	[95% Co	nf.	Interval]
Aff   Belief   AffXBelief   _cons	232689 4837987 .0977215 7.132278	.2063445 .26034 .0525599 1.045872	-1.13 -1.86 1.86 6.82	0.265 0.070 0.070 0.000	64828 -1.0081 008139 5.02578	.5 17	.1829101 .040553 .2035826 9.238772

Figure 42: Regression of Aff(ordance) on Belief

### . regress Adhere Aff Agency AffXAgency

Source	SS	df	MS		per of obs . 45)	; = =	49 4.89
Model   Residual	10.2184868 31.3478397	3 45	3.4061622 .69661866	7 Prok 1 R-sc	) > F quared R-squared	=	0.0050 0.2458 0.1956
Total	41.5663265	48	.86596513		MSE	=	.83464
Adhere	Coef.	Std. Err.	t	P> t	[95% C	onf.	Interval]
Aff Agency AffXAgency _cons	1135334 .2622998 .0216227 4.565583	.3988689 .4178315 .0787534 2.01078	-0.28 0.63 0.27 2.27	0.777 0.533 0.785 0.028	91689 5792 13699 .51566	256 148	.6898299 1.103856 .1802401 8.615503

Figure 43: Regression of Aff(ordance) on Agency

### . regress Adhere Con Mot ConXMot

Source   Model Residual	SS .88018161 40.6861449	df 3 45	MS .29339387 .904136554	F(3 Prol	per of obs , 45) p > F quared R-squared	= = =	49 0.32 0.8076 0.0212 -0.0441
Total	41.5663265	48	.865965136	Root	t MSE	=	.95086
Adhere	Coef.	Std. Err.	t	P> t	[95% Con	f.	Interval]
Con Mot ConXMot _cons	0421469 150803 .0325358 6.119774	.2142862 .2763637 .055405 1.077935	-0.55 0.59	0.845 0.588 0.560 0.000	4737414 7074281 0790555 3.9487		.3894475 .4058221 .1441271 8.290847

Figure 44: Regression of Con(text) on Mot(ivation)

### . regress Adhere Con Belief ConXBelief

Source    Model   Residual    Total	SS .964441475 40.6018851 41.5663265	df 3 45 48	MS .32148049 .90226411 .86596513	- F(3, 2 Prob 2 R-so - Adj	per of obs 45) 0 > F quared R-squared MSE	= = = =	49 0.36 0.7848 0.0232 -0.0419 .94988
Adhere	Coef.	Std. Err.	t	P> t	[95% Co	nf.	Interval]
Con   Belief   ConXBelief   _cons	.2030566 .1613811 0405974 5.050185	.2376968 .3018131 .0641236 1.212841	0.85 0.53 -0.63 4.16	0.397 0.595 0.530 0.000	275689 446501 16974 2.60739	6 9	.6818024 .7692638 .0885543 7.492973

Figure 45: Regression of Con(text) on Belief

### . regress Adhere Con Agency ConXAgency

Source	SS	df	MS		per of obs	=	49 5.31
Model   Residual	10.86838 30.6979465	3 45	3.62279333 .68217659	3 Prob 9 R-sc	F(3, 45) Prob > F R-squared Adj R-squared		0.0032 0.2615 0.2122
Total	41.5663265	48	.865965136		t MSE	=	.82594
Adhere	Coef.	Std. Err.	t	P> t	[95% Co	nf.	Interval]
Con   Agency   ConXAgency   _cons	2821813 .2509379 .0373864 5.030977	.3667365 .2861342 .0635394 1.553724	-0.77 0.88 0.59 3.24	0.446 0.385 0.559 0.002	-1.02082 325366 090588 1.90161	1 5	.4564639 .8272418 .1653613 8.160338

Figure 46: Regression of Con(text) on Agency

### . regress Adhere Norm Mot NormXMot

Source	SS	df	MS		per of obs	=	49 0.20
Model   Residual	.545404186 41.0209223	3 45	.18180139 .911576052	5 Prok 2 R-sc	) > F quared R-squared	=	0.8962 0.0131 -0.0527
Total	41.5663265	48	.865965136		MSE	=	.95476
Adhere	Coef.	Std. Err.	t	P> t	[95% Co	nf.	Interval]
Norm   Mot   NormXMot   _cons	.1025168 .099448 0388464 5.667572	.3093491 .1934503 .0699946 .8767793	0.33 0.51 -0.55 6.46	0.742 0.610 0.582 0.000	520544 290180 179822 3.90164	8 7	.7255779 .4890769 .1021299 7.433496

Figure 47: Regression of Norm on Mot(ivation)

### . regress Adhere Norm Belief NormXBelief

Source	SS	df	MS		er of obs	=	49
Model   Residual	.318520704 41.2478058	3 45	.106173568 .916617907	Prob R-sq	F(3, 45) Prob > F R-squared Adi R-squared		0.12 0.9504 0.0077 -0.0585
Total	41.5663265	48	.865965136		MSE	=	.9574
Adhere	Coef.	Std. Err.	t	P> t	[95% Cd	onf.	Interval]
Norm   Belief   NormXBelief   _cons	0186241 0071644 0062159 6.072117	.3368917 .2143651 .0723429 .840775	-0.03 -0.09	0.956 0.973 0.932 0.000	697158 438917 15192 4.37870	79 22	.6599106 .4245892 .1394902 7.765525

Figure 48: Regression of Norm on Belief

#### . regress Adhere Norm Agency NormXAgency

Source	l ss	df	MS		per of obs	=	49 5.12
Model Residual	10.5777174 30.9886092	3 45	3.52590578 .68863576	8 Prok 6 R-sc	F(3, 45) Prob > F R-squared Adj R-squared		0.0039 0.2545 0.2048
Total	41.5663265	48	.865965130		MSE	=	.82984
Adhere	Coef.	Std. Err.	t	P> t	[95% Cor	f.	Interval]
Norm Agency NormXAgency _cons	284294   .2683728   .0431002   4.702696	.4643208 .2222455 .0857565 1.207763	-0.61 1.21 0.50 3.89	0.543 0.234 0.618 0.000	-1.219484 1792527 1296223 2.270135	, ,	.6508961 .7159982 .2158226 7.135256

Figure 49: Regression of Norm on Agency

# 15.3 Analysis of new survey instruments

Because of shortcomings in the quantitative research, no conclusions could be drawn on the validity of any new or modified survey instruments. While future research may prove more fruitful, at this stage there will be no further discussion of these.

# **15.4 Summary**

A logical step-by-step process was followed in an attempt to extract any significant relationships; none were found.

The next chapter closes the quantitative research with some conclusions.

### 16 Quantitative Research Conclusions

### 16.1 Introduction

This chapter sums up and draws conclusions on the quantitative research. Its structure is as per Figure 50.

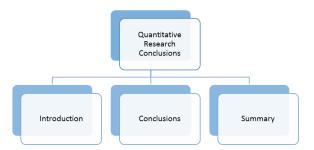


Figure 50: Chapter structure

#### 16.2 Conclusions

This first step towards testing the qualitative process of adherence by means of the quantitative process was unsuccessful in identifying significant moderating effects. Issues arose at several points in the procedure.

Firstly, the overall purpose of the survey was blurred. While it was aimed at understanding the interrelationships between adherence factors, there was also a desire to capture much more detail on reasons for non-adherence than was necessary for this purpose alone.

Secondly, the pilot test results were not exploited. This meant that the survey contained too many questions for most people to be willing to complete. This should have been noticed and addressed, but since no statistical analysis was performed on the pilot results there was no basis for exclusion of any questions.

Thirdly, the methods used to invite participants did not reach far enough into the overall population to consider the selection process random. Instead, point solutions to boost participation were used, resulting in both convenience and snowball sampling. One reason for this was that most recruitment was performed online thus disenfranchising the section of the population which was unable to

receive such invitations. This meant that even if statistically significant results had been obtained it would still not have been possible to make broad claims for the general population.

Fourthly, the means of completing the survey was not generally accessible. An online survey may have encouraged the young to participate rather than the more mature, all things being equal. It also meant that in the developing world it enabled only the more relatively wealthy, who had smartphones, to participate; this therefore missed out the true Base-of-the-Pyramid residents who were much more fairly represented in the qualitative results.

Fifth and finally, there were too few respondents to achieve statistically valid results. The analysis process used was statistically sound but it did not yield any valid results.

# **16.3 Summary**

This first attempt to test the quantitative process was unsuccessful. This was as a result of shortcomings at some points in the survey procedure from design to implementation. However, the appropriate statistical approach was taken in the analysis of the results.

The value and validity of the qualitative process of adherence is not negated by disappointing quantitative results. The quantitative process of adherence may yet be found to be relevant.

### 17 Conclusions

### 17.1 Introduction

In this final chapter the research threads are brought together, views of the qualitative and quantitative processes discussed, and some answers proposed for the question, what is adherence from a process perspective? Following this, managerial implications are raised, limitations discussed and recommendations for follow-on work suggested.

The structure of this chapter is as in Figure 51.



Figure 51: Chapter structure

#### 17.2 Conclusions

#### 17.2.1 Literature review

It became clear through the literature review that there has been little theoretical research into adherence. Most has had practical bent, and the relatively few which have employed theory as a basis have used an expectancy-value one such as the Theory of Planned Behaviour.

As a result of the literature review, six adherence factors were identified for taking forward: beliefs, motivation, agency, context, norms and affordance. These were applied to a process derived through the lens of Service-Dominant Logic. This led to the creation of an initial process of adherence. This was then examined for validity in the qualitative research.

#### 17.2.2 Qualitative research

Two Qualitative Propositions were created.

Qualitative Proposition 1 proposed that the interviews were satisfactorily comprehensive and could therefore be used as a basis for endorsing the soundness of the second proposition and therefore the process of adherence. This was approached in two ways. The first examined the interviews to establish whether interview responses adequately covered all of the six factors of adherence. The second used a bottom-up method to determine the number of causes from the list of 55 causes in the ASA & ASCPF (2006) report, Adult Meducation. Forty-five of the 55 causes were found, the other ten requiring either an undue level of personal exposure by the interviewees or the possibility of personal assessment and recording by the interviewer. In addition, 19 causes of adherence not mentioned in the list of 55 causes were identified from the interviews. The results of these validations were considered to be in good alignment with Proposition 1 and therefore Qualitative Proposition 2 was supported.

Proposition 2 proposed that the initial process was a useful way of understanding the process of adherence. Performing and analysing 30 qualitative interviews showed good alignment with the process, and as a result a refined version was proposed as the qualitative process of adherence. This was on the basis that the interviews did in fact comprehensively cover the ground, which was the subject of the first proposition.

One important facet of this research is the focus on adherence as an individual act rather than an average of all adherence events for a patient or even a cohort of patients. The viewpoint of Service-Dominant Logic inherently supports this perspective, which allows a focus on what factors and rules are uppermost in the patient's mind at that point of adherence. While this is innately a qualitative approach, it may provide greater insights into causes of non-adherence in practice, and therefore guide adherence interventions more effectively than repeated quantitative approaches which often produce inconclusive results.

#### 17.2.3 Quantitative research

This research was performed in order to operationalise the major factors of adherence. A quantitative process of adherence was created from the qualitative process which was suitable for statistical analysis. The research failed to provide support to validate that process.

### 17.3 What is adherence from a process perspective?

The purpose of the thesis was to attempt to answer the question, what is adherence from a process perspective? Based on this research there are potentially three answers.

#### 17.3.1 Answer 1: the triad

This is the coming-together of patient and medicine in context to create value, controlled by the three rules of medicine instructions, contextual norms and patient beliefs. It might be visualised as in Figure 52.

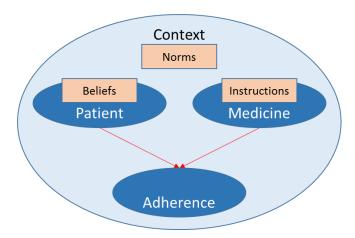


Figure 52: Triad perspective of adherence

This answer in itself is a development of previous adherence research. So far, research has been focused on dyads such as patient and context or patient and medicine. The three parts of the triad, with the three controlling rules, have not been brought together in this way before. However, this is quite a simple definition.

## 17.3.2 Answer 2: the qualitative process of adherence

This is a significant further development of the first answer. It brings in details which cannot be shown in the triad perspective. Based on the depiction of Service-Dominant Logic, it positions the six factors of adherence into a view of the process in order to show how they dovetail. In addition, the use of a lens which encompasses the full adherence process from absence to post-consumption value assessment significantly extends the theories currently applied to adherence research.

It also shows some of the irreducible complexity innate in adherence when it is understood as a complex interaction of service systems. Through this depiction it can be understood just why adherence is so hard to pin down empirically and perhaps explains why there is so much inconclusive research. Using a view of the process like this can provide a basis for future empirical research since it can illuminate reasons for results. Its depiction is repeated here as Figure 53.

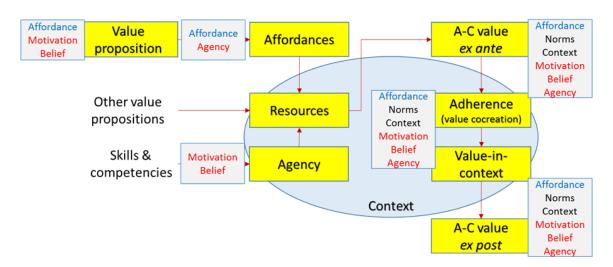


Figure 53: Qualitative process of adherence

This is the view of the process which provides the greatest insights into adherence. It has been developed through a range of theoretical and practical measures. This process is considered to be the most developed of the three presented here. It goes well beyond previous theories, which have here been built on to gain a theoretical understanding of the adherence process. Therefore

this theoretical view of the adherence process is proposed as the answer to the question, what is adherence from a process perspective?

# 17.3.3 Answer 3: the quantitative process of adherence

This is a deconstruction of the qualitative process. Although its first test had no success it may still provide a basis for future adherence research. It pictures a series of factors moderating the patient's attempt at adherence. Each attempt is enabled or driven by beliefs, motivation and agency, and is potentially moderated by the medicine's affordance, the context, and the norms arising from relevant service ecosystems. One attraction of this view of the process is its extensibility, since other factors can be introduced. However, as a simplified statistical model it cannot give the fine-grained insights of the qualitative view of the process. It is repeated here as Figure 54.

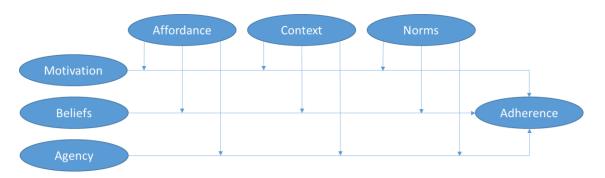


Figure 54: Quantitative process of adherence

# 17.4 Contributions to knowledge

This research has made the following seven contributions to knowledge. Firstly, it has extended existing partial theories to establish a theoretical view of the adherence process. This qualitative theoretical view describing the process of adherence is considered to be a significant step forward from the theories currently applied to adherence research. This qualitative process of adherence process could potentially inform future empirical research and so improve the effectiveness of interventions aimed at increasing adherence.

Secondly, it has delivered a new understanding of adherence as an individual opportunity to be adherent rather than as an average of all consumption opportunities over a course of treatment. This permits a closer focus on just what enables or hinders adherence at a point in time and this in turn allows the investigation to be at a point when as many as possible of the factors affecting adherence are as constant as possible. This encourages a qualitative approach to adherence research. It could potentially reduce the need for quantitative research, since that has been shown to be weak in determining actual causes and therefore in the selection of optimum interventions in various contexts.

Thirdly, it has enhanced the general understanding of adherence. It can now be seen as a complex interrelationship of factors involved from the initial recognition of absence that triggers motivation right through to the *ex post* assessment of value gained from being adherent. To enable this, it has visualised adherence as a complex interaction of service systems, and so has developed a theoretical view of the adherence process which goes beyond the expectancy-value theories and permits the point of adherence to be included theoretically for the first time.

Fourthly, it has developed a quantitative perspective for the adherence process. This view could potentially inform quantitative research into adherence.

Fifthly, it has contributed a pictorial representation of the flow of Service-Dominant Logic which has not been presented before. It has also incorporated and positioned service ecosystems and the Integrative Framework of Value within the flow. This representation was used as the basis for developing the qualitative theoretical view of the process of adherence.

Sixthly, although the interviewees were not intended to be representative samples of their populations, the qualitative interviews suggested that reasons for non-adherence are broadly the same – although not necessarily for the same reasons – across developed and developing worlds. This surprising finding may have implications for future medicine formulations, since assumptions on agency and context may be causing adherence issues in the developed world in the same ways as for the developing world.

Seventhly, but less importantly from a theoretical perspective, is the addition of 19 new causes to the existing 55 causes of non-adherence (ASA & ASCPF 2006).

# 17.5 Managerial implications

Adherence is critical to clinical outcomes. Therefore there are several implications emerging from this research.

Firstly, it is clear that there are several factors affecting adherence, and that the qualitative process of adherence can help in understanding their interrelationships and where they act in the end-to-end process of adherence. These insights should help pharmaceutical manufacturers to make their medicines more applicable to the patients in their contexts whom they are targeting with each medicine. In particular, medicines which more completely address contextual challenges could be more successful in raising adherence than those which at present might be perceived as "one size fits all". There is much discussion about manufacturers becoming more patient-centric; this provides a means by which it might be possible to deliver on that commitment.

Secondly, and extending the first, it has become clear from the research that some adherence factors are effectively "mirror images" of each other. For example, a patient's context may not be contributing sufficient resources to permit adherence, but if the medicine's affordance were to be enhanced then consumption might still be able to occur. Perhaps a patient's context cannot provide food or water, but if these could be incorporated into the medicine in some way then the patient may still be able to be adherent. Similarly, the patient's agency may be limited – perhaps not being able to open the bottle or to swallow large pills – but enhancements to the medicine's value proposition might address such limitations. This is potentially a very valuable area to investigate as manufacturers aim to deliver outcomes rather than just inputs as part of "beyond the pill" initiatives (Bloomberg 2014; Dasgupta & Wenzel 2013).

### 17.6 Limitations

There are two limitations which hampered the research. The first was the inability to perform more ethnographic research as part of the qualitative research. By removing the possibility of speaking to most interviewees face to face it reduced the opportunity to gain the deepest insights. It also prevented other types of interviews such as with medical staff, family members, and the like. It may be that a face-to-face approach would have uncovered further causes of non-adherence. However the interviews, even though mostly remote, did succeed in gaining insights into a large range of causes of non-adherence and so lent weight to the validity of the qualitative process of adherence.

The second was the quantitative survey. There were major weaknesses in this part of the research. Firstly, an insufficient number of people were recruited for the survey. This was likely to have been caused by the means of reaching potential respondents. The use of social media, on-campus advertising and word-of-mouth requests did not exhaust the range of methods which could have been used. The hoped-for 500 or more people was reduced to just less than 200 as a result.

Secondly, the respondents who did participate in the survey were not a random sample that was representative of the population as a whole. Despite using the survey tool recommended by the university, it would in fact have been challenging to obtain a representative sample. To achieve a more random sample it may have been necessary to engage a company specialising in surveys. The method of presenting the survey online, which required the use of a laptop or smartphone, is likely to have inhibited the participation of those who were not computer-literate or who did not have access to a smartphone. This is in contradistinction to the qualitative interviews, which reached a much more representative sample because only a basic phone was required.

Thirdly, when respondents did engage with the survey it was found that most of them did not fully complete it. This was most likely due to the inappropriately large number of questions in the survey – almost 100. This number was caused by

including too many items for each of the seven instruments. While most of the instruments themselves were generally sound since they had already been utilised in surveys performed by others, their use in this combination was excessive. In addition, in an attempt to gather as much detail as possible based on the rich data obtained from the qualitative interviews, further items were appended to some instruments which only exacerbated the issues.

Fourthly, when responses were examined in detail it was found that the number of respondents completing the survey was only 49. This is a small number for any survey, and wholly inadequate for drawing any conclusions from a survey of almost 100 questions involving seven instruments.

Fifth and finally, some of the 49 respondents who completed the survey appeared not to provide thoughtful answers to all questions. Upon inspection of the raw data there was found to be evidence of question after question being given the same score of either 1 or 7 on the 7-point Likert scale. This is also manifest in very high standard deviations in the instrument summaries (Stata "summarize" command) for most questions; this can be seen in the figures in Appendix C.2. This in itself suggests that the results of the quantitative analysis should be discounted.

Therefore, a combination of an excessively long questionnaire and a limited number of respondents meant that the quantitative research was unlikely to provide any statistically significant results. This turned out to be the case. Although valid processes were used to analyse the results, no useful conclusions can be drawn that have any relevance to the quantitative process.

Nevertheless, although the quantitative process has not been validly tested by this research it may yet be shown to be valuable in future research if used with a more appropriate set of items for each instrument.

# 17.7 Recommendations

These are considered in two parts. Firstly, research that could follow on directly from this thesis. Secondly, wider investigations in associated areas.

#### 17.7.1 Direct follow-on research

There are five particular themes. Firstly, the quantitative research could possibly be performed again. It would require several elements to be amended. (1) The questionnaire must be much shorter so as to focus on only the major aspects of each factor. (2) Many more responses should be captured. (3) Respondents should be a more representative sample of the population; this may require the survey to be offered in more ways, to permit everyone to respond whether they are online or not – from the Base-of-the-Pyramid to the older generation.

Secondly, research into factors of adherence was necessarily simplified for this research such that only six factors were examined in detail. It was assumed that instructions were one of the medicine's affordances, and that the patient-clinician relationship was one of the institutions of the norm of the medicine supply service ecosystem. It may be valuable in future research to break these out so that they can be explored independently. While this will not negate the findings in this research and may simply confirm the assumptions, it may uncover further richness of detail which will contribute to the ongoing development of the theoretical view of the process of adherence.

Thirdly, as an extension to the second point it would potentially be useful to perform further qualitative research face to face with interviewees in their contexts. This would potentially reveal greater depth and so permit further refinements and developments of the process of adherence. Looking more deeply into the factors would perhaps expose further layers of detail that would permit a greater understanding of each one.

Fourthly, it would be beneficial to review the results of this research with members of the various ecosystems such as clinicians, NGOs, pharmaceutical manufacturers and suppliers. It is expected that they would receive benefit from the insights already gained which would permit them to deliver medicines which are more suitable for their patients in their own contexts.

Fifth and finally, it may be useful to explore adherence from the perspective of it being the responsibility of the patient to decide on their level of adherence and therefore being responsible for their own health outcomes. There has been significant time expended on improving adherence without necessarily recognising patient autonomy. Once again, qualitative research would be one way of achieving these insights.

#### 17.7.2 Wider extensions

There are two possible opportunities to take this research into adherence beyond what has been achieved here.

The first is in response to medicine consumption being a form of consumption. If it is accepted that all consumption of a consumable is performed in context and governed by the three rules of instructions, norms and beliefs, then there is potential benefit in researching how adherence can be applied to other consumables.

For example, it could be argued that this could beneficially be applied to the understanding of consumption of illicit drugs. The application of the qualitative view of the process of adherence could be used to gain insights and therefore define more theoretically supported interventions. Another example might be the consumption of fruit and vegetables, looking through the lens of the qualitative process at why some people do not or cannot eat their "five a day".

Secondly, the application of behavioural theories to adherence may imply that there is less difference between consumption and behaviour than might at first sight be the case. In fact, it seems reasonable to consider behaviour as being "consumption" of a "consumable" in context governed by rules.

The "consumable" will not be edible but could, perhaps, be a piece of flat-pack furniture to be assembled. The assembly context, the constructor's beliefs, the contextual norms, the flat-pack's affordances, could all be relevant to being adherent to the instructions, and so be worth considering when designing interventions which might make assembly easier.

Perhaps it might be less physical than furniture. Consumption of the experience

of reading a recipe book might be another. Is it read for pleasure or to guide food

preparation? Similar questions as above can be asked when considering how the

book is experienced in various ways, from both the pleasure perspective and its

use for cooking. How are the pictures consumed? How are the recipes followed

in users' many contexts? Perhaps the book's affordances could be enhanced if

these things were known.

Applying the qualitative view of the adherence process to wider consumption and

to behaviour might therefore be fruitful avenues of future research.

**17.8 Summary** 

This chapter has brought the thesis to a conclusion. It has reprised the findings

of the literature review and the empirical research. It has proposed the qualitative

theoretical view of the process of adherence as an answer to the overarching

research question, what is adherence from a process perspective? It has

delineated the contributions to knowledge of the work. And it has discussed

management implications, research limitations and recommendations for further

research.

Deo gratias; soli Deo gloria.

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# **Appendices**

# **Appendix A: Service-Dominant Logic Foundational Premises**

Table 39 lists the Foundational Premises of Service-Dominant Logic. The table draws together definitions from the three papers Vargo & Lusch (2008), Lusch & Vargo (2014) and Vargo & Lusch (2015).

**Table 39: Foundational Premises of Service-Dominant Logic** 

FP	Foundational Premise (axioms highlighted)	Comment/explanation
1	Service is the fundamental basis of exchange	The application of operant resources (knowledge and skills), "service", as defined in S-D logic, is the basis for all exchange. Service is exchanged for service
2	Indirect exchange masks the fundamental basis of exchange	Because service is provided through complex combinations of goods, money, and institutions, the service basis of exchange is not always apparent
3	Goods are a distribution mechanism for service provision	Goods (both durable and non-durable) derive their value through use – the service they provide
4	Operant resources are the fundamental source of strategic benefit	The comparative ability to cause desired change drives competition
5	All economies are service economies	Service (singular) is only now becoming more apparent with increased specialization and outsourcing
6	Value is co-created by multiple actors, always including the beneficiary	Implies value creation is interactional
7	Actors cannot deliver value but can participate in the creation and offering of value propositions	Enterprises can offer their applied resources for value creation and collaboratively (interactively) create value following acceptance of value propositions, but cannot create and/or deliver value independently
8	A service-centered view is inherently beneficiary-oriented and relational	Because service is defined in terms of customer- determined benefit and co-created it is inherently customer oriented and relational
9	All social and economic actors are resource integrators	Implies the context of value creation is networks of networks (resource integrators)
10	Value is always uniquely and phenomenologically determined by the beneficiary	Value is idiosyncratic, experiential, contextual, and meaning-laden
11	Value co-creation is coordinated through actor-generated institutions and institutional arrangements	"[S-D Logic] is a narrative of cooperation and coordination in ecosystems, as well as the reconciliation of conflict between them. Institutions are instrumental in these cooperation and coordination activities by providing the building blocks for increasingly complex and interrelated resource-integration and service-exchange activities in nested and overlapping ecosystems organized around shared purposes" (Vargo & Lusch 2015)

# **Appendix B: Qualitative Research**

# **B.1 Participant Information Leaflet (PIL)**



#### PARTICIPANT INFORMATION LEAFLET (December/2014)

Study Title: Research phase 1: Why do people not take their medicine when they should?

Investigator(s): Peter Ward, supervised by Professor Irene Ng

Introduction

You are invited to take part in a research study. Before you decide, please read PART 1 of this leaflet on why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. If you think you would like to participate then PART 2 gives you more details. Please take sufficient time to decide whether you want to take part.

#### PART 1

#### What is the study about?

I am researching why people sometimes don't take their medicine when the prescription tells them to. I will use what I learn to see how drug companies and medicine distribution networks can change what they provide to people to help improve adherence.

#### Do I have to take part?

No. It is entirely up to you to decide. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

#### What will happen to me if I take part?

You will have been approached by a colleague and asked to take part. He/she will have given you this leaflet and a consent form. If you decide to take part then you need to complete and sign the consent form and give it to my colleague to copy and send to me. You need to tell my colleague what phone number I can call you on and agree a time and date.

At the time of the interview I will call you by phone from a private room. You should find a quiet, distraction-free place where you cannot be overheard. We will talk for about 30 minutes. I will ask you some questions and we will discuss your answers. You are free to answer or to refuse any question. I will record our discussion so I can transcribe it (write down what we said) later.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part? There are no known disadvantages from this study. If you feel uncomfortable in any way or at any time you are completely free to stop participating. It will take about 30 minutes of your time.

#### What are the possible benefits of taking part in this study?

There are no immediate benefits from participating in this work. However, there is potentially a large benefit to people everywhere from the study if it leads to new information that makes medicine easier to consume.

#### What will happen when the study ends?

When the study ends, I will analyse all the information I have collected to identify new problems that prevent people from taking medicine when they should. This information will then be shown to industry to see how it can respond. This may lead to medicines being made easier to take.

The information I collect will only be used by me for this study and possible future studies on the same subject. It will be anonymised so nobody will be able to identify you from anything that I publish.

#### Will my taking part be kept confidential?

Yes, unless you choose to inform others.

#### What if there is a problem?

I will aim to address any complaint about the way you have been dealt with during the study or any possible harm that you suffer. You can also report problems to my university.

V3, 23/1/15

Figure 55: Participant Information Leaflet for qualitative research (1 of 2)



#### PART 2

#### Who is organising and funding the study?

This study is organised and funded by the University of Warwick in the UK.

#### What will happen if I don't want to carry on being part of the study?

Participation in this study is completely voluntary. If you refuse to take part it will not affect you in any way. If you do decide to take part in the study we will ask you to sign a consent form which states that you have agreed to participate. However, even if you agree to take part you may still withdraw from the study at any time without it affecting you in any way. You have the right to leave the study completely and to decline any further contact by study staff.

#### What if there is a problem?

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue please contact the Director of Delivery Assurance (details below).

#### Who should I contact if I wish to make a complaint?

We aim to resolve any complaint about the way you have been dealt with during the study or any possible harm you might have suffered. Please address your complaint to the person below, who is a senior official of the University of Warwick entirely independent of this study:

Director of Delivery Assurance Registrar's Office University of Warwick Coventry CV4 8UW UK

All letters will receive an initial response within five working days of being received. To speed up our response to your complaint you can submit it by email (together with any supporting evidence or documentation) to <a href="mailto:complaints@warwick.ac.uk">complaints@warwick.ac.uk</a>.

#### Will my taking part be kept confidential?

Yes. At the end of the data collection phase all input will be stored on a secure computer (with secure backup) and in a locked cabinet. In these forms it will only be accessible to me, my university supervisors and examiners. If I subsequently write papers with other researchers using the same data they will only have access to anonymised input.

#### What will happen to the results of the study?

The new ideas from my research will be discussed with drug companies and drug distributors. They will be included in my PhD thesis and in academic papers. I will not include your name in any references to, or quotations from, your input.

#### Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC), reference REGO-2014-1295.

#### What if I want more information about the study?

If you have any questions about any aspect of the study or your participation in it that are not answered by this leaflet, please contact:

Researcher: Peter Ward, p.m.ward@warwick.ac.uk, +44 7711 058871 Supervisor: Professor Irene Ng, irene.ng@warwick.ac.uk, +44 7775 927728

Thank you for taking the time to read this participant information leaflet.

V3, 23/1/15

Figure 56: Participant Information Leaflet for qualitative research (2 of 2)

# **B.2 Consent form**



# BIOMEDICAL AND SCIENTIFIC RESEARCH ETHICS COMMITTEE CONSENT FORM

Study Number:	Research phase 1	
Title of Project:	Why do people not tak	te their medicine when they should?
Name of Researcher(s):	Peter Ward, supervise	d by Professor Irene Ng
Patient Identification Nu	imber for this study:	
		Please initial all box
December/2014 for th	ead and understand the info e above study. I have had th tions and have had these an	ne opportunity to consider the
	participation is voluntary and g any reason, without my me	that I am free to withdraw at edical or legal rights being
looked at by individua authorities, where it is	vant sections of my data coll ls from The University of Wa relevant to my taking part ir ndividuals to have access to	this research. I give
4. I understand that my	data may be used in subseq	uent research.
5. I agree to the interview	w being recorded.	
6. I agree to take part in	the above study.	
Name of Participant	Date	Signature
Name of Participant	Date	Signature
Peter Ward		
Name of Person taking consent	Date	Signature

Figure 57: Consent Form for qualitative research

# **B.3 Research approval letter**



Figure 58: BSREC approval for qualitative research

### **B.4 List of interviewees**

See Table 40 for a detailed list of interviewees. Local costs were converted to UK pounds on 12/12/15. Dates are dd/mm/yy.

Table 40: Interviewee details

Code	No.	Sex	Age range	Country	Medicine	Cost	Location type	Distance/ cost to obtain	Interview type	Interview date	Transcript date
EG	01	F	20-40	Egypt	Cough medicine		City	Close	F2F	30/04/15	12/05/15
KN	01	М	20-40	Kenya	Antibiotics	£0.03	Village		Phone	27/02/15	11/06/15
KN	03	М	40-60	Kenya	Amoxycilin		Village	1km	Phone	27/02/15	12/06/15
KN	04	М	20-40	Kenya	Malaria tablets	£3.23	Village	5km/£2.59	Written	27/02/15	07/05/15
KN	05	М	60+	Kenya	Coartem	£0.13	City	Close	Phone	27/02/15	15/06/15
KN	06	F	20-40	Kenya	Malaria tablets		Town	Close	Phone	27/02/15	11/05/15
KN	07	М	20-40	Kenya	Pain killer, curatives	£0.66	Village	Close	Written	15/04/15	07/05/15
KN	08	М	40-60	Kenya	Malaria (AL)	£0.97	Village	2km	Written	03/06/15	03/06/15
KN	09	М	20-40	Kenya	Panadol	£0.84	Village	2km	Written	26/05/15	08/06/15
KN	10	М	40-60	Kenya	Chrotin B	£1.29	Village	6km	Written	26/05/15	08/06/15
KN	11	F	20-40	Kenya	Quinine	£2.91	Village	2km	Written	26/05/15	08/06/15
KN	12	F	20-40	Kenya	Panadol	£0.45	Village	4km	Written	26/05/15	10/06/15
KN	13	F	20-40	Kenya	Flugone	£1.29	Village	3km/£1.94	Written	26/05/15	10/06/15
KN	14	М	40-60	Kenya	Cold Cups	£0.32	Village	1km	Written	26/05/15	10/06/15
KN	15	М	20-40	Kenya	Ibuprofen	£1.62	Village	2km	Written	02/06/15	10/06/15
KS	01	F	20-40	Kazakhstan	Repronact	£2.09	Village	3.5km	F2F	02/02/15	10/05/15
NG	01	М	40-60	Nigeria	Artesunate	£1.49	Town	Close	Phone	28/02/15	11/05/15
TZ	01	М	40-60	Tanzania	Coartem		Village	4 hours	Phone	26/02/15	11/05/15

Code	No.	Sex	Age range	Country	Medicine	Cost	Location type	Distance/ cost to obtain	Interview type	Interview date	Transcript date
TZ	02	М	60+	Tanzania	Paladrin	£1.53	Town	Close	Phone	26/02/15	15/06/15
TZ	03	М	60+	Tanzania	for Stomach Abscess	£0.31	Town	Close	Phone	27/02/15	11/06/15
TZ	04	F	40-60	Tanzania	Malafin, Panadol, Maleratab	£1.53	Town	10-15 mins	Phone	26/02/15	12/06/15
UG	01	М	40-60	Uganda	Quinine	£3.95	Village	30km/£6.59	Written	02/03/15	07/05/15
UK	01	F	<20	UK	Roacutane, Erythromycin	Free	Village	5km	F2F	30/12/14	07/05/15
UK	02	М	40-60	UK	(multiple)	Free	Town	1km	F2F	01/01/15	07/05/15
UK	03	F	>60	UK	Metformin	Free	Town	1km	F2F	01/01/15	14/06/15
UK	04	М	>60	UK	Antibiotics	£8.20	City	5km	F2F	07/01/15	12/06/15
UK	05	М	>60	UK	for Angina	Free	Town	2km	F2F	04/02/15	14/06/15
UK	06	F	>60	UK	Sulfasalazine, Methotrexate	Free	Town	2km	F2F	04/02/15	15/06/15
ZI	01	F	20-40	Zimbabwe	Amoxycilin		Village		Written	25/03/15	07/05/15
ZM	01	М	40-60	Zambia	Coartem	Free	Village	Close	Phone	26/02/15	11/05/15

# **B.5 Interview transcripts**

Every interview was transcribed and imported into Nvivo10 for analysis. Analysis was also performed manually directly from the transcripts. The transcripts are not reproduced here due to their length but they are available with certain conditions to those with a legitimate research need.

# **B.6 Interview coding: Qualitative Proposition 1a**

Table 41 and Table 42 in this section contain analysis codes, extracts from the interviews, and the interview from which each extract was taken. The first table is for developing countries and transition countries (in this case, Egypt and Kazakhstan) – together referred to here as the developing world – while the second is for developed countries (in this case, UK). The country definitions are from the United Nations (UN Development Policy and Analysis Division 2016). Although separate analyses for different "worlds" was not part of this research, the two tables are separate to facilitate possible future research which may which to look at the differences.

In these two tables, codes are defined as "positive" or "negative". As an example of what "positive" and "negative" mean, see these two interview extracts:

Effects, positive, side, none: "[Any side effects?] Not to my knowledge" (UK06)

Taste, negative, bad: "I took one but couldn't take more because of the nasty taste" (ZM01).

Table 41: Interview coding with random order of codes, developing world

Transcription code	Interview example	Interview ref.
Distance, positive, close	pharmacies in every street just down the road from our flat But if I need to get it from a pharmacy it's a kilometre	EG01
	I walk, I take one minute to get to the health centre Not very far. Just walk to get them	KN03 KN05
	It was 2km away 2km from my home	KN06 KN08

Transcription code	Interview example	Interview ref.
	2km from my home	KN09
	2km from home	KN11
	About 1km	KN15
	Pharmacy isn't far, about 10 minute walk from my house	KN14
	Just nearby. Two minutes	KZ01
	Just a few meters two minutes' walk	NG01
	Not too far	TZ02
	Only 10 minutes' walk to the [small] pharmacy when you want to go to	TZ03
	the big pharmacy it takes about 15 minutes	TZ04
Instructions, negative, foreign language, verbal	I don't understand colloquial Arabic	EG01
Instructions, negative,	I think we figured out the written instructions	EG01
foreign language,	you really don't understand the reading	EG01
written	people who can't even read	EG01
Utensils, negative,	I don't think there was a spoon. I think we had to buy it separately	EG01
missing		
People, positive,	Probably my husband was there sometimes	EG01
present	Mum and my younger sisters were there	KN04
	It's better for someone to make sure you get the full dose	KN06
	Mother and brothers were there	KN09
	Grandmother was there with me as I have no parents	KN11
	I was with the physician only	KN13
	Family members	KN14
	With a friend	KN15
	My parents	KZ01
	My wife is the one who was always reminding me to take it	TZ03
Content, negative,	you really don't have a clue what's in it [it's] at the back of your head that it could be anything	EG01
unknown	I don't like taking medicinebecause of the idea that it's chemicals	NG01
Branding, positive,	natural ones are better than synthetic  I suppose the branding just makes you trust it more	EG01
known		E001
Motivation, negative, last resort	I think I sort of used it as a last resort  Just like when I'm really sick, I'm like distressed for getting better	EG01 KN03
	makes me take the pills	1/1/07
	Urge to get healed	KN07
	I was physically weak and mentally disturbed I felt desperate	KN08
	Totally disturbed Eager to know its [effect]	KN10
	Felt hard to use since I don't like medicines	KN15
	I'd have taken anything	KZ01
Diagnosis, negative, foreign language, verbal	would have helped if the person that we saw could speak English	EG01
Taste, negative, bad	Sometimes obviously the taste of the medicine	EG01
	the taste of the drugs	KN03
	I don't like it. I don't like taking medicine because of the taste	NG01
	They don't taste well when you swallow them. Bad taste	TZ03
	[not completing the full dosage] is primarily caused by difficulty in	ZI01
	taking the medicine due to taste I took one but couldn't take more because of the nasty taste	ZM01
Effects, negative, bad	it's not good for you	EG01
=oto, mogativo, bad	Sometimes it can harm the body	KN10
	if I take the medicine it weakens my body for some time	KN15
	in fact the body constitution was changed	TZ02
	The medicine itself was reactive	TZ02
	the Coartem seems to be a bit too much for me	ZM01
	I hear about these doctors saying about how conventional medicines affect the liver	ZM01
Effects, negative, side,	there's all these side effects	EG01
general	I don't like taking medicine because there's side effects	NG01
-	taking tablets irritates them	TZ01
Beliefs, negative,	"Paracetamol doesn't work for you because you keep taking it"	EG01
others, too dependent	so I'll have to bargain for half a tablet of Paracetamol if my temperature	KZ01
omora, too dependent	is high as a kid, they didn't believe in medicine much	INCU I
Beliefs, negative, profit, pharma	this thing about the pharmaceutical industry and how they're making profit	EG01
Beliefs, negative, profit,	the natural remedy people are also making their profit as well	EG01

Transcription code	Interview example	Interview ref.
Stop, negative, better	I wouldn't even [complete the course] if the GP said "make sure you finish the course"	EG01
	after 3 days you feel like you're ok. You're like, "No I don't need to get more medicines then"	KN03
	Many people [stop when they feel better]	KN06
	Sometimes I'll take it according to the prescription but sometimes I stop when I feel better	NG01
	Sometimes I feel that I'm feeling better	TZ01
	When they see they're a little better they stop taking the tabs	TZ01
	then I got well feeling well before finishing the dose	TZ03
	When one takes the medicine and gets better maybe he feels fine, so it's difficult for him to finish the dose	TZ04
	And some, when they feel better, then drop the medicine [not completing the full dosage] is primarily caused by early signs of	TZ04 ZI01
	healing For some, I think the moment they feel better they choose not to take	ZM01
Ocal marks law	any more	IZNIGO
Cost, positive, low	At the hospital sometimes we don't pay	KN03
	About 100 Tz Shillings [£0.03, \$0.05]	KN01 KN05
	Ksh20 [£0.13, \$0.20]	
	Ksh70 [£0.47, \$0.72]	KN12 KN14
	Ksh50 [£0.33, \$0.52]	TZ03
	Tsh1000 [£0.30, \$0.46] We go to the hospitals. They give out malaria tablets for free	TZ03
	For things like Coartem they don't really charge	ZM01
Instructions, positive,	The prescription should say when the medicine should be taken	KN01
clear, written	They write on the cover	KN03
clear, writterr	Because it was written 2x3 meaning 6 tabs per day	KN04
	I knew reading the prescription	KN07
	The prescription was indicated on the cover	KN07 KN09
		KN12
	I knew by the doctor's prescription Yes it was written 2x2. Consume with a lot of water	
	I followed the physician prescriptions	KN13 KN15
Reminder, positive,	I use an alarm for night	KN01
alarm	Some medicines I have to put alarm on reminding myself not to forget this	KZ01
Taste, negative, bitter	It's bitter	KN01
, 0 ,	I think there should be much reduce the bitterness	KN01
	Some medicines are bitter this makes it hard to consume	KN07
	too bitter	KN09
	Bitterness of the medicine it is so bitter	KN11
	Differriess of the inedicine It is so biffer	IXINII
		KN12
	I hate medicine. They are bitter Reduce the bitterness of the tabs	
	I hate medicine. They are bitter	KN12
	I hate medicine. They are bitter Reduce the bitterness of the tabs	KN12 KN04
	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty	KN12 KN04 KN07 KN09
	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour.	KN12 KN04 KN07
	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the	KN12 KN04 KN07 KN09 NG01
	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose	KN12 KN04 KN07 KN09 NG01 TZ04
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so big	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 TX04 KN01 KN03 KN08 KN09 KN11 KN01
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN01 KN01
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 TX04 KN01 KN03 KN08 KN09 KN11 KN01
Size, negative, big	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 TX04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09
	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01
Formulation, negative,	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose  It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets I fear injections!	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01
Formulation, negative,	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose  It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets I fear injections! I prefer medicines than the injection	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01
Formulation, negative, injection	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets I fear injections! I prefer medicines than the injection I prefer oral	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01
Formulation, negative, injection  Effects, negative, side,	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets I fear injections! I prefer medicines than the injection I prefer oral I've read about side effects like your digestive system	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01 KN01 KN03 KN07 EG01
Formulation, negative, injection	I hate medicine. They are bitter Reduce the bitterness of the tabs It becomes easier to take if medicine is tasty [Make them] a bit sweet Better something that is sweet Some are very, very some are not sweet, you know. They're so sour. I think if maybe sweeter, then somebody can swallow it easier And some, because the medicine is soooo bitter, drop it from taking the whole dose It's big One is like the size of the pill This tablets are in large sizes and so swallowing becomes a problem The size is too big Size of this medicine is so bigat least the size of it should be moderate to make easier swallowing Reduce the largeness of the tabs A bit small[er] [not completing the full dosage] is primarily caused by difficulty in taking the medicine due to sizeyou swallow them and it feels like you haven't swallowed them and you wonder how you're going to take the next tablets I fear injections! I prefer medicines than the injection I prefer oral	KN12 KN04 KN07 KN09 NG01 TZ04 TZ04 KN01 KN03 KN08 KN09 KN11 KN01 KN04 KN09 ZI01 ZM01

Transcription code	Interview example	Interview ref.
	I feel like vomiting	KN06
	l could feel dizziness in me	TZ02
	they take medicines and end up vomiting	TZ02
	you become very tired	TZ04
	It makes me feel so dizzy, a lot of noise in the ears, chilling of the body,	UG01
	loss of appetite, sometimes vomiting. This makes [me] feel bad, dodge the dosage	
	even produce a smell when urinating or on the skin or in sweat	ZI01
	Sick for a whole week and all that, the headaches, stomach stuff, the pains. I thought not to go through all that [by consuming the medicine]	ZM01
Taste, positive, sweet	The ones we have around here are very sugary so very easy for someone to take	KN03
	I liked it	KN14
Distance, negative, far	If I need to get from the hospital I have to go 4km away	KN03
	5km from home. Travelled by Nissan at a cost of ksh400 [\$3.95, £3]	KN04
	good pharmacy shops are not available in the rural areas	KN07
	Almost 6km	KN10
	4km from home	KN12
	3km from home. Used a motorbike which costed ksh200 [£1.33, \$2.06]	KN13
	The problem is the pharmacy doesn't open on Monday so we had to drive to her home about 3.5km away	KZ01
	4 hours [travel time]	TZ01
	It's 30km to and from, to the pharmacy. \$10 [£6.57] transport	UG01
Beliefs, negative,	when I'm there I'm not feeling comfortable to take the pills so stigma	KN03
others, stigma	itself can cause or make someone not to take the medicines stigma is a major issue	
	I sometimes I never just wanted to take medicine, because that I feared for stigma sometimes when I wanted to take that medicine I could just hide	TZ02
	People are afraid of that stigma when people have HIV and AIDS they always try to hide it from people	TZ02
Food, positive, present	Use of porridge	KN11
, , , ,	Porridge	KN12
	I had eaten	KN15
	My mum was cooking	KZ01
	Yes [I have food]. Normally you have to eat for medicine	NG01
	I do take it with porridge	TZ04
Food, negative, absent	If you don't have something to eat you won't take the drug you have nothing to eat	KN03
	take them after every meal. This was not possible due to poorness. We cannot afford 3 meals a day so it was hard to take the tabs in the afternoon	KN04
	I did not take it at that time because I was hungry and tired	KN04
	No [I did not consume] I was hungry	KN11
	I wasn't getting enough food I really felt that drug if I hadn't eaten	KZ01
	It's difficult to have enough food to visit the prescription	TZ01
	We Africans take some medicines with not enough food	TZ01
	They require a lot of drinks and eating well but we are poor we can't afford most of the requirements. Sometimes we have a single meal a day	UG01
Beliefs, negative, foreign origin	I don't like taking medicine because it's foreign	NG01
Beliefs, negative, lack of faith	if you don't have that [faith to be healed] then you'll have to take medicine	TZ02
Course, negative, long	sometimes prescriptions take long time, many days for you to finish the dose	KN03
	I wished I could consume them once and over I thought I would be given medicine to consume once and over In general medicines are difficult for me to take. The dosage may be long	KN04
	It becomes easier to take medicine does not taking too long	KN07
	To get relieved at once	KN09
	Others they are not following the information [from the doctor]	TZ04
	They take long to heal, it's a long dosage of 3-6 days	UG01
Stop, negative, replaced by other	maybe going for other drugs to see if they treat quicker I end up not taking the other dose	KN03
Stop, negative, keep	They act like emergency for my family	KN03
οιορ, πεgative, κεερ	I keep it just in case I get a re-occurrence of same symptom. Then I take	NG01
	the leftover when I cannot get to buy another Here in Africa, many people keeping a dose	TZ01

Transcription code	Interview example	Interview ref.
Motivation, positive,	I don't want to feel sick again tomorrow so I must complete the medicine	KN06
stay well	If maybe I could default then I could have been maybe in danger	TZ02
	In general I think it's good for taking all malaria tabs because if you don't then you can feel worse when malaria attacks again	TZ04
Motivation, positive, get well	Hopes came with the medicine I used my illnesses as a reason to take it right away	KN13
	I knew soon I will be well	KN14
Effects, positive, others	Also, experience from other people. If maybe my [family] used the same drug and she got well, definitely that helps me to finish	KN03
Regimen, negative,	You realise it's hard for me to wake up in the midnight to take pills	KN03
unacceptable	Personally I go for prescription guidelines [as cause of failure]. They easily make me not to finish the prescription	KN03
	And with the tablets, they feel like there's too many	ZM01
Cost, negative, high	Ksh500 [\$4.95, \$3.75] was the cost of the medicine	KN04
	Ksh150 [£1, \$1.53]	KN08
	Ksh130 [£0.87, \$1.33]	KN09
	Ksh200 [£1.34, \$2.05]	KN10 KN11
	Ksh450 [£3.01, \$4.60] Ksh300 [£2, \$3.09] to buy the medicine	KN13
	Ksh250 [£2, \$5.09] to buy the medicine  Ksh250 [£1.67, \$2.57]	KN15 KN15
	Fairly expensive for Kazakhstanabout £3-4 they tend to look at how you're dressed	KZ01
	450 Nira [£1.49, \$2.27]	NG01
	malaria medicine is not affordable to a lot of people	NG01
	Tsh2000, 5000 [£0.58, \$0.91; £1.46, \$2.27] depending on the quantity	TZ02
	but mainly in hospitals there are less malaria tabs so most people go	TZ04
	to buy them in the pharmacy there are some tablets from India, there	
	are some tabs from Western countries and then there are some tablets	
	from the local, from within the country. So within the country you can find	
	them at tsh1000 [£0.29, \$0.45]. And then tabs from outside the country goes to tsh3000 [£0.88, \$1.36] to tsh5000 [£1.47, \$2.27]	
	some cannot afford the full dose	TZ04
	\$6 [£3.94] medicine	UG01
Instructions, negative, misunderstood	I know how to take Coartem we take two tabs, two times a day	KN05
Instructions, positive,	They explained it clearly how to take it	KN05
clear, verbal	I knew by listening	KN07
	My teacher told me to follow the doctor's prescription	KN11
	the doctor showed me the correct way	KN14
	I just listened to a doctor so that I can follow what he has told me	TZ01
	I followed the instruction given to me by the doctor	TZ03
	I realised its importance after being taught the effects of that medics when taken wrongly	UG01
Course, positive,	I take it up to the last one	KN05
acceptable	I take it until I use all the tablets	NG01
	I do follow the information	TZ04
Effects, negative, others	I just see them, they want to go vomit	KN06
Stop, negative, discarded	They throw it away, because you can't go on taking the medicine	KN06
Access, negative, hard	with curative I found after going to various pharmacy shops I did not obtain the medicine [until] the third shop	KN07 KN08
Formulation, positive,	Personally I would go for liquid	KN03
liquid	People around here with children they like syrups	KN07
•	If they can convert this tabs into syrup the better	KN08
Regimen, negative,	I could not actually imagine there will be a prescription or directive on	KN08
unexpected	how to take the medicine I thought I could just consume regardless	
	I thought I will get better at that moment	KN11
	I get a medicine to drink once and get cured	KN13
		1/1/1/1
	I had planned to take large amounts	KN14
	I had planned to take large amounts It was not in my plan to consumer it according to the prescriptions	UG01
Water, negative, absent		
Water, negative, absent People, negative,	It was not in my plan to consumer it according to the prescriptions  The medicine was to be consumed with a lot of water which I did not have sufficient of I lacked water I was thinking of taking the medicine	UG01

Transcription code	Interview example	Interview ref.
	[not completing the full dosage] is primarily caused by difficulty in taking the medicine due to lack of monitoring of the sick by fit family members	ZI01
Smell, negative, bad	This medicine has a smell and this smell surely disturbs me a lot when taking the medicine	KN08
	Some medicines do emit a pungent smell that will cause nausea and vomiting [Is the smell sufficient to stop taking?] Yes bro absolutely! As soon as you open the package you actually feel the strong smell	ZI01
Beliefs, positive, confidence	I had confidence that it will relieve my pain	KN09
Water, positive, present	Water helped me to consume	KN09
	Water helped	KN11
	Water	KN12
	with a lot of water. Yes, I have enough water	TZ03
	I do take it with tea Yes, yes. I have access	TZ04 ZM01
	Yes, my eldest sister, they take their medicine with Coca-Cola	ZM01
Formulation, positive,	[Easier] through syringe	KN09
injection	I prefer the injection before because I don't like the taste of medicine	NG01
,	in the east region [of Africa] there are some people the majority who prefer injections	TZ02
D.P. (	The other [sister], they prefer the injections to tablets	ZM01
Beliefs, positive, others	I had been informed about its advantages	KN10
Instructions, negative, unclear, written	So even though the packaging said something else, the doctor specified "something something 3 times". I had to ask my parents to decode the curvier writing. [without that] it would have been a bit of a guess	KZ01
Regimen, positive, acceptable	I didn't mind for instance at night-time to wake up	KZ01
Regimen, negative,	[Prefer] once per day	KN12
complex	[Prefer to] take many dosage for a quick recovery	KN14
	I would like to take it whenever I go to bed	KN15
	I had to make sure that they eat in the morning the first two tablets of the day were regular and then not	KZ01
	When I go to the clinic, I just get the diagnosis and I go for other medications there were too many tablets. So I took my pawpaws and I was ok in 2 days. The malaria was all gone	ZM01
Regimen, negative,	And then once I forgot, I misplaced it, so I missed it	KZ01
forgot	The time I forgot to take it. I repeated the dose that I did not take	TZ03
Instructions, negative, unclear, verbal	So it was a very vague direction so I didn't assume that it was critical	KZ01
Routine, negative, absent	if your day gets mixed up with night and you're really not sure any more what to stick to	KZ01
	That occurs so much in Africa! Maybe you can miss in that case in the evening, or forget in the morning and then take in the afternoon then miss in the evening, or someone can take 6 at once!	TZ04
	some people I know only take them in the night	TZ04
Routine, positive, present	I tend to be pedantic about those things I've been given a task I'm going to do this I might as well do it properly	KZ01
	I try as much as possible to get it at home. After my meal, my breakfast, and when I return from work	NG01
	I make sure that I am in the house	TZ01
	I just started following the prescription strictly I was at home	TZ02
	I remember if I want to eat I have to take medicine	TZ03
Cost pogative barbal	[Are you always at home?] Yes, it is	TZ04
Cost, negative, herbal, low	the herbal [malaria medicines] are very cheapmedicines from China food supplement cheaper Or if you don't have managery you just can take some least medicine	NG01 NG01
Poliofe pogetive value	Or if you don't have money you just can take some local medicine	TZ04 TZ01
Beliefs, negative, value Stop, negative, busy	Sometimes they say that the tablets are weak  I was occupied maybe from work	TZ01
Stop, negative, busy	Because maybe they're occupied	TZ03
Storage, negative,	maybe the people being lazy can just put them where children are	TZ04
unsafe	reaching and then the children can consume them it can be more dangerous	1207
Stop, negative, run out	some cannot afford the full dose	TZ04

Table 42: Interview coding with random order of codes, developed world

Transcription code	Interview example	Interview ref.
Distance, positive, close	Walk	UK02
	We don't live too far away, about half a mile	UK03
	10 yards. The doctor's and the chemist's are together	UK04
	About a quarter of a mile	UK05
	About a mile	UK06
People, positive,	[What made applying it possible?] Someone else did it	UK01
present	Obviously have breakfast together and dinner	UK02
	with the family	UK04
	I took the responsibility on so she didn't have to think about it	UK04
	Yes. "Have you taken your tablets?"	UK05
Content, negative,	I wouldn't want to be putting a lot of stuff into my body that I didn't know	UK06
unknown	what it was doing	
Motivation, negative, last resort	I never want to take drugs only because he said to take them I took them	UK04
	I was sad that I was prescribed it for the illness I was said to have, but I took it	UK05
Stop, negative, better	I don't take the prescribed dose every day I can go a fortnight without	UK05
	taking them when I haven't got the symptoms I'll knock them I'll take them for several days until I notice it's subsided and then I'll stop	UK05
Cost, positive, low	They're all free?] Yes	UK01
51, positivo, 10W	[It didn't cost you anything?] No	UK03
	Fortunately [wife] had an exemption	UK04
	Free	UK05
	[You don't have to pay?] No	UK06
Instructions, positive,	[Easy to understand?] Yes	UK01
clear, written	It was written on the doctor's prescription. And a copy on the packet	UK03
	I think the label on the tablet bottle said that	UK04
	it has a little leaflet inside	UK05
	Because it was on the box that the tablets came in	UK06
Size, negative, big	The Sulfasalazine are quite large and hard but no, no problem just the size, but as long as my tea is not too hot	UK06
Food, negative, absent	Sometimes when I remembered there wasn't another chance to eat	UK01
Stop, negative, keep	I don't feel any ill effects by not taking them I've got those in stock that I can draw on if I need	UK05
Motivation, positive, stay well	I don't want to have any problem coming up because I've forgotten to take them or decided not to take the medicine he's prescribed. That would be foolish	UK02
	And from starting to take those tablets I have had no swelling and no pain. I still take them	UK06
	I was extremely grateful that there was something I was being given to	UK06
	keep down the pain, and it did	111/00
	I don't want to risk a return to the swelling and pain I would not risk stopping taking them	UK06
Motivation, positive, get	[Positive results encouraged you to carry on?] Yes	UK03
well	I was happy because it would take away a lot of the pain	UK04
	The results were absolutely magical, marvellous, a miracle	UK06
Regimen, negative, unacceptable	I didn't put it on my back very often because it was hard to get to I had to clean it before, so that was annoying as well	UK01
Cost, negative, high	Yes, £7 or whatever	UK04
Instructions, negative, misunderstood	It said take 2 twice a day but I didn't know what that meant	UK01
	I think he must have said "take one per day", which I did every morning	UK03
Instructions, positive,		LUZOE
Instructions, positive, clear, verbal	I was told how to take them	UK05
Instructions, clear, verbal Course, positive,	I was told how to take them  [Take in accordance with the prescription?] Yes	UK05 UK01
Instructions, clear, verbal  Course, acceptable  positive, positive,	[Take in accordance with the prescription?] Yes	UK01
Instructions, clear, verbal  Course, positive, acceptable  Water, negative, absent People, negative,		
Instructions, clear, verbal  Course, positive, acceptable  Water, negative, absent  People, negative, absent	[Take in accordance with the prescription?] Yes  Sometimes. Not always [And when you didn't apply it you were on your own?] Yes	UK01 UK01 UK01
Instructions, clear, verbal  Course, positive, acceptable  Water, negative, absent People, negative,	[Take in accordance with the prescription?] Yes  Sometimes. Not always [And when you didn't apply it you were on your own?] Yes  [take them all with water?] Yes	UK01 UK01 UK01 UK02
Instructions, clear, verbal  Course, positive, acceptable  Water, negative, absent  People, negative, absent	[Take in accordance with the prescription?] Yes  Sometimes. Not always [And when you didn't apply it you were on your own?] Yes  [take them all with water?] Yes I took it with a drink	UK01 UK01 UK01 UK02 UK03
Instructions, clear, verbal  Course, positive, acceptable  Water, negative, absent  People, negative, absent	[Take in accordance with the prescription?] Yes  Sometimes. Not always [And when you didn't apply it you were on your own?] Yes  [take them all with water?] Yes	UK01 UK01 UK01 UK02

	on code	Interview example	Interview ref.
Regimen, acceptable	positive,	breakfast time is set and teatime is set so twice a day fits in quite happily with that	UK04
		I didn't need to take one 3 times a day. I could take the 3 at breakfast time	UK06
Regimen, complex	negative,	I had to take it with food 8 hours apart, an hour before I ateI had to take it during the gap between my lessons before lunch but that's actually 50 minutes and then on the bus as soon as I got on, for tea there were a lot of times I actually forgot	UK01
		[If you had a choice of how to take?] I'd say not with food Especially the hour before food, you don't know when you're next going	UK01 UK01
		to have foodit was a real concoction of working out what she needed at each time so I devised a spreadsheet	UK04
		It was something that sounds simple but was such an onerous task day after day	UK04
		You might have run out of 50s but you've got 25s so you give three 25s or combinations of it was an absolute logistical nightmare	UK04 UK02
Regimen, forgot	negative,	Perhaps very very occasionally if we've been out to a late dinner I might have forgotten	
La atau attau a		Well very rarely	UK03
Instructions, unclear, verb	negative, pal	and the pharmacist might have grunted that at me as he passed it over	UK04 UK04
Routine,	negative,	Initially, yes, but everything was so fluid that it became evident that it didn't really matter too muchchange in routine, like on a weekend or I was staying in someone's	UK01
absent	riegative,	house, I'd forget to take itbut if we ate upstairs or in a different room I wouldn't take it	UK01
Routine,	positive,	one in the morning and one at night. Getting up and going to bed.	UK01
present	poolaro,	Part of the routine  Just sort of when getting up or going to bed it jogged my memory	UK01
		I put it in the dining room because I had to take it with a meal	UK01
		I take certain ones with a drink with my breakfast or before my breakfast, and I have some in the evening also before I take a drink	UK02
		I fill the containers for 7 days [then] I don't forget them I'm capable of remembering what should be in each	UK02
		I always took the packet out and took it with my breakfast	UK03
		So it was quite easy as long as I'd got them with me In the morning with breakfast with a cup of tea evening meal again with a cup of tea	UK03 UK04
		In a morning [At breakfast?] Yes	UK05
		[Do you have them in a box with flaps?] Yes. [Does that help?] Very much so	UK05
		I got a little box with a week of separated compartments I don't have to think about it in a morning	UK06
O: ::		At the breakfast table	UK06
Stop, negativ		We had to eke them out instead of having like 2 tablets twice a day we had to have 1	UK04 UK01
Access, posi	live, easy	Mum picked it up Walk, or perhaps drive in if I'm going to town it's a standing order	UK02
		I Walk, of perhaps universiting following to towns It's a standing order	
		it's very simple Collected from Boots they have an arrangement by which you collect	UK03
		it's very simple	
		it's very simple Collected from Boots… they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No	UK03 UK03
		it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist	UK03 UK03 UK05
Motivation	negative	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call	UK03 UK03 UK05 UK06
Motivation, tired	negative,	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired	UK03 UK03 UK05 UK06 UK01
	negative,	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired  There didn't seem to be a lot of point [in consuming] I don't know really what I'm taking tablets for I doubt his diagnosis	UK03 UK03 UK05 UK06
tired Beliefs,		it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired  There didn't seem to be a lot of point [in consuming]	UK03 UK03 UK05 UK06 UK01
tired Beliefs, pointless Reminder,	negative,	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired  There didn't seem to be a lot of point [in consuming] I don't know really what I'm taking tablets for I doubt his diagnosis actually If I've no pain then I don't need it preventing	UK03 UK03 UK05 UK06 UK01 UK01 UK01
Beliefs, pointless Reminder, general Instructions, compliant	positive,	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired  There didn't seem to be a lot of point [in consuming] I don't know really what I'm taking tablets for I doubt his diagnosis actually If I've no pain then I don't need it preventing Some kind of reminder, especially when I'm staying over  I have been advised by my doctor to take these and therefore I'm quite happy to take whatever he has prescribed I just do as I'm asked to do	UK03 UK05 UK06 UK01 UK01 UK05 UK01 UK05 UK01
tired Beliefs, pointless Reminder, general Instructions,	positive,	it's very simple Collected from Boots they have an arrangement by which you collect regular medicines [It wasn't inconvenient?] No We just go and pick it up from the chemist It could be delivered to me but I'm usually out so I call [When you didn't apply it, you were?] Tired  There didn't seem to be a lot of point [in consuming] I don't know really what I'm taking tablets for I doubt his diagnosis actually If I've no pain then I don't need it preventing  Some kind of reminder, especially when I'm staying over  I have been advised by my doctor to take these and therefore I'm quite happy to take whatever he has prescribed	UK03 UK05 UK05 UK06 UK01 UK01 UK05 UK01

Transcription code	Interview example	Interview ref.
	I find tablets pretty easy	UK05
	[What you've got is fine?] Yes	UK06
Size, positive, small	[Any problems?] No. [Small enough?] Swallow them down	UK05
Effects, positive, side,	[Any side effects?] Not to my knowledge	UK06
none		

### **Appendix C: Quantitative Research**

### **C.1 Survey questions**

This section lists the questions included in the survey. These were postfixed with demographic questions relating to age, sex, and country where the medicine-taking experience occurred.

Key to Table 43:

N/A Not applicable

N—A Never – Rarely – Occasionally – Sometimes – Frequently – Usually – Always

SD—SA Strongly disagree – strongly agree

Table 43: Final list of survey questions

Variable	Origin of question	Question	Scale All 7-point Likert unless specified *=inverted
N/A	Own	Please enter the name or a description of the medicine you are thinking of	(Text input)
N/A	Own	What form did your medicine take?	Tablet/capsule Chewable Sublingual Powder/granules Syrup Solution/emulsion Injection Inhaler Ointment/cream Spray Drops Pessary/ suppository
N/A	Own	How often did you have to take it?	Less than once a week Once a week Several times a week Once a day Twice a day Three or more times a day
N/A	Own	How long was the course of treatment?	Single dose 1-3 days 4-7 days 7-14 days 15-28 days More than 28 days

Variable	Origin of question	Question	Scale All 7-point Likert
			unless specified *=inverted
	<b>34 questio</b> a particular t	ns) ime when you had this medicine, select the fr	equency that applies
Agency1	MUSE	I am able to take my medicine on time	N A
Agency2	MUSE	I am able to remember to take all my medicines	N—A N—A
Agency3	MUSE	I am able to set a schedule to take my medicines each day	N—A
Agency4	MUSE	I am able to take my medicines every day	N—A
Agency5	MUSE	I am able to ask my pharmacist questions about my medicine	N—A
Agency6	MUSE	I am able to understand my pharmacist's instructions for my medicine	N—A
Agency7	MUSE	I am able to understand instructions on medicine bottles	N—A
Agency8	MUSE	I am able to get all the information I need about my medicine	N—A
Agency9	Own	I am able to take my medicine without help	N—A
Agency10	Own	I am able to know when to take my medicine	N—A
Agency11	Own	I am able to understand why I should take my medicine	N—A
Aff1a	Own	There is nothing about the medicine itself which puts me off	N—A
Aff1b	Own	This medicine has features which stop me taking it	N—A *
Aff1c	Own	The medicine itself gives me problems taking it	N—A *
Aff1d	Own	I have no problems taking the medicine itself	N—A
Aff2	Own	There is something about this medicine's taste that puts me off	N—A *
Aff3	Own	There is something about the tablet size of this medicine that stops me taking it	N—A *
Aff4	Own	There is something about this medicine's smell that stops me taking it	N—A *
Aff5	Own	There is something about the form of this medicine that stops me taking it	N—A *
Aff6	Own	There is something about the duration of course of treatment that stops me taking this medicine	N—A *
Aff7	Own	There is something about this medicine's packaging that stops me opening and taking it	N—A *
Aff8	Own	I do not take my medicine because I know the bad side-effects it has had on others	N—A *

Variable	Origin of question	Question	Scale All 7-point Likert unless specified *=inverted	
Aff9	Own	I don't take this medicine because it is made by a profit-making company	N—A *	
Aff10	Own	I don't take this medicine because it contains unknown chemicals	N—A *	
Con1a	Own	In my situation I have everything I need to take this medicine	N—A	
Con1b	Own	In my situation I am missing something at the time I need to take it	N—A *	
Con1c	Own	In my circumstances when the time comes to take this medicine I have all the things I need	N—A	
Con1d	Own	In my situation I have everything available to me to allow me to take this medicine	N—A	
Con2	Own	In my circumstances, at the time I take this medicine I have the food I need to allow me to do so	N—A	
Con3	Own	In my situation, at the time I take this medicine I have the water I need to allow me to do so	N—A	
Con4	Own	In my circumstances, at the time I take this medicine I have the utensils (spoon, syringe, etc) I need to allow me to do so	N—A	
Con5	Own	In my situation, at the time I take this medicine I have the help I need to allow me to do so	N—A	
Con6	Own	In my circumstances, at the time I take this medicine I have the containers (cup, measuring jug, etc) I need to allow me to do so	N—A	
Con7	Own	In my situation, I do not take this medicine because of the stigma attached to it or to my illness	N—A *	
Thinking st statements	?	cular medicine, how much do you agree with	·	
Belief1	DAI-30	I believe that I don't need to take this medicine once I feel better	SD—SA *	
Belief2	DAI-30	I believe that for me, the good things about this medicine outweigh the bad	SD—SA	
Belief3	DAI-30	I believe that I feel strange, "doped up", on this medicine	SD—SA *	
Belief4	DAI-30	I believe that even when I am not in hospital I need this medicine regularly	SD—SA	
Belief5 NORM	DAI-30	I believe that if I take this medicine, it's only because of pressure from other people	SD—SA *	
Belief6	DAI-30	I believe that I am more aware of what I am doing, of what is going on around me, when I am on this medicine	SD—SA	

Variable	Origin of	Question	Scale	
Variable	question	Question	All 7-point Likert	
			unless specified	
Dalia (7	DALOO	I haliana that talian this madising will do	*=inverted	
Belief7	DAI-30	I believe that taking this medicine will do me no harm	SD—SA	
Belief8	DAI-30	I believe that I take this medicine of my own free choice	SD—SA	
Belief9	DAI-30	I believe that this medicine makes me feel more relaxed	SD—SA	
Belief10	DAI-30	I believe that I am no different on or off this medicine	SD—SA *	
Belief11	DAI-30	I believe that the unpleasant effects of this medicine are always present	SD—SA *	
Belief12	DAI-30	I believe that this medicine makes me feel tired and sluggish	SD—SA *	
Belief13	DAI-30	I believe that I take this medicine only when I feel ill	SD—SA *	
Belief14	DAI-30	I believe that this medicine is a slow-acting poison	SD—SA *	
Belief15	DAI-30	I believe that I get along better with people when I am on this medicine	SD—SA	
Belief16	DAI-30	I believe that I can't concentrate on anything when I am taking this medicine	SD—SA *	
Belief17	DAI-30	I believe that I know better than the doctors when to stop taking this medicine	SD—SA *	
Belief18	DAI-30	I believe that I feel more normal on this medicine	SD—SA	
Belief19	DAI-30	I believe that I would rather be ill than taking this medicine	SD—SA *	
Belief20	DAI-30	I believe that it is unnatural for my mind and body to be controlled by this medicine	SD—SA *	
Belief21	DAI-30	I believe that my thoughts are clearer on this medicine	SD—SA	
Belief22	DAI-30	I believe that I should keep taking this medicine even if I feel well	SD—SA	
Belief23	DAI-30	I believe that taking this medicine will prevent me from having a breakdown	SD—SA	
Belief24	DAI-30	I believe that it is up to the doctor to decide when I should stop taking this medicine	SD—SA	
Belief25	DAI-30	I believe that things that I could do easily are much more difficult when I am on this medicine	SD—SA *	
Belief26	DAI-30	I believe that I am happier and feel better when I am taking this medicine	SD—SA	
Belief27 NORM	DAI-30	I believe that I am given this medicine to control behaviour that other people (not myself) don't like	SD—SA *	
Belief28	DAI-30	I believe that I can't relax on this medicine	SD—SA *	
Belief29	DAI-30	I believe that I am in better control of myself when taking this medicine	SD—SA	
Belief30	DAI-30	I believe that by staying on this medicine I can prevent myself getting sick	SD—SA	

Variable	Origin of question	Question	Scale All 7-point Likert unless specified *=inverted	
Belief31 NORM	Own	I believe that I have to take this medicine because my religious faith has not cured me	SD—SA *	
Belief32 <b>NORM</b>	Own	I believe that it is not good to be seen taking this medicine	SD—SA *	
Belief33	Own	I believe that natural remedies are safer for me to take than this medicine	SD—SA *	
Belief34	Own	I believe that I am getting better because of taking this medicine	SD—SA	
Belief35	Own	I believe that I can get better in other ways than taking this medicine	SD—SA *	

Motivation (16 questions)
Thinking of the particular time when you had this medicine, why were you motivated to take it?

Mot1	CMOTS	I am motivated because other people think that it's a good idea for me to take it	N—A		
Mot2	CMOTS	I am motivated because my friends think I should take it	N—A		
Mot3	CMOTS	I am motivated because I don't want to upset people close to me who want me to take it	N—A		
Mot4	CMOTS	I am motivated to satisfy people close to me who want me to get better	N—A		
Mot5	CMOTS	I am motivated because I would feel guilty if I were not doing anything about my illness	N—A		
Mot6	CMOTS	I am motivated because I would feel bad about myself if I didn't continue my course	N—A		
Mot7	CMOTS	I am motivated because I should have a better understanding of myself	N—A		
Mot8	CMOTS	I am motivated because it is important for me to continue the course until it's finished	N—A		
Mot9	CMOTS	I am motivated because I would like to make changes to my current situation	N—A		
Mot10	CMOTS	I am motivated because I believe that eventually it will allow me to feel better	N—A		
Mot11	CMOTS	I am motivated because I believe that taking it will allow me to deal with things better	N—A		
Mot12	CMOTS	I am motivated because I believe it's a good thing to find solutions to my illness	N—A		
Mot13	CMOTS	I am motivated because through taking it I've come to see a way that I can approach different aspects of my life	N—A		
Mot14	CMOTS	I am motivated because through taking it I feel that I can now take responsibility for making changes in my life	N—A		

Variable	Origin of question	Question	Scale All 7-point Likert unless specified *=inverted
Mot15	CMOTS	I am motivated because I feel that the changes that are taking place through taking it are becoming part of me	N—A
Mot16	CMOTS	I am motivated because I value the way it allows me to make changes in my life	N—A
	e (4 question the particular	time when you had this medicine, select the f	requency that applies
Aunerera	Own	I take my medicine according to the instructions	N—A
Adhere1b	Own	I take my medicine correctly	N—A
Adhere1c	Own	I take my medicine as prescribed	N—A
Adhere1d	Own	I take my medicine as I have been instructed	N—A
Total = 89 d	questions		

### C.2 Statistical summary data

This section provides high-level statistical description of each measured variable arising from the survey whose contents are provided above.

#### . summarize Adherela Adherelb Adherelc Adhereld

Max	Min	Std. Dev.	Mean	l Obs	Variable
7	1	1.322233	6.040816	i 49	Adhere1a
7	2	1.214286	5.673469	j 49	Adhere1b
7	2	1.189523	6.040816	j 49	Adhere1c
7	2	1.154701	6	j 49	Adhere1d

Figure 59: Summary of Adhere(nce) items

# . summarize Affla Afflb Afflc Affld Aff2 Aff3 Aff4 Aff5 Aff6 Aff7 Aff8 Aff9 Aff10

Max	Min	Std. Dev.	Mean	l Obs	Variable
7	1	2.044779	3.836735	49	Affla
7	1	1.884641	4.897959	49	Afflb
7	1	1.790945	4.795918	49	Afflc
7	1	2.184126	4.020408	49	Affld
7	1	2.195582	4.632653	49	Aff2
7	1	1.975832	4.632653	49	Aff3
7	1	2.172219	4.897959	49	Aff4
7	1	1.670828	5	49	Aff5
7	1	1.770891	4.77551	49	Aff6
7	1	1.922389	5.367347	49	Aff7
7 7 7	1 1 1 1	1.702339 1.31998 2.097131	5.346939 6.387755 5.653061	49   49   49	Aff8 Aff9 Aff10

Figure 60: Summary of Aff(ordance) items

## . summarize Agency1 Agency2 Agency3 Agency4 Agency5 Agency6 Agency7 Agency8 Agency9 Agency10 Agency11

Max	Min	Std. Dev.	Mean	Obs	Variable
7 7 7 7 7	1 2 1 1	1.673879 1.425592 1.814295 1.354006 2.03101	4.897959 5.265306 4.428571 5.428571 4.571429	49 49 49 49 49	Agency1 Agency2 Agency3 Agency4 Agency5
7 7 7 7 7 7	1 2 1 1 1	1.475422 1.288357 1.638192 2.127924 1.634294	5.897959 6.081633 5.061224 5.183673 5.530612	49 49 49 49 49	Agency6 Agency7 Agency8 Agency9 Agency10
7	1	1.760537	5.673469	+   49	Agency11

Figure 61: Summary of Agency items

. summarize Belief1 Belief2 Belief3 Belief4 Belief6 Belief7 Belief8 Belief9 Belief10 Belief11 Belief12 Belief13 Belief14 Belief15 Belie > f16 Belief17 Belief18 Belief19 Belief20 Belief21 Belief22 Belief23 Belief24 Belief26 Belief28 Belief29 Belief30 Belief33 Bel > ief34 Belief35

Variable	Obs	Mean	Std. Dev.	Min	Max
Belief1	49	4.612245	1.977123	2	7
Belief2	49	2.734694	1.468779	1	7
Belief3	49	3.285714	1.892969	1	7
Belief4	49	4.346939	2.194226	1	7
Belief6	49	3.734694	1.765119	1	7
Belief7	49	3.367347	1.943942	1	7
Belief8	49	4.346939	2.126725	1	7
Belief9	49	4.265306	1.966125	1	7
Belief10	49	3.346939	1.854623	1	7
Belief11	49	3.979592	2.135901	1	7
Belief12	49	3.816327	1.965043	1	7
Belief13	49	4.877551	2.006579	1	7
Belief14	49	3.612245	1.966557	1	7
Belief15	49	4	2	1	7
Belief16	49	3.530612	1.969582	1	7
Belief17	49	2.918367	1.789282	1	6
Belief18	49	3.755102	1.8988	1	7
Belief19	49	2.306122	1.474846	1	7
Belief20	49	3.571429	2.03101	1	7
Belief21	49	3.795918	1.825509	1	7
Belief22	49	4.163265	2.124725	1	7
Belief23	49	4.387755	1.923715	1	7
Belief24	49	3.122449	1.932536	1	7
Belief25	49	3.408163	2.040408	1	7
Belief26	49	3.734694	1.944817	1	7
Belief28   Belief29   Belief30   Belief33   Belief34	49 49 49 49 49	3.530612 4.081633 3.897959 3.653061	1.883061 1.945473 2.084115 2.116906 1.903943	1 1 1 1 1	7 7 7 7 7
Belief35	49	3.693878	1.828069	1	7

Figure 62: Summary of Belief items

. summarize Con1a Con1b Con1c Con1d Con2 Con3 Con4 Con5 Con6 Con7

Max	Min	Std. Dev.	Mean	Obs	Variable
7	1	1.911298	5.183673	49	Conla
7	1	1.764156	4.632653	49	Conlb
7	1	2.052458	4.530612	49	Conlc
7	1	1.890497	4.734694	49	Conld
7	1	2.067114	4.346939	49	Con2
7	1	1.789045	5.612245	49	Con3
7	1	2.263095	4.408163	49	Con4
7	1	2.318038	3.959184	49	Con5
7	1	2.077986	4.877551	49	Con6
7	1	1.791182	5.571429	49	Con7

Figure 63: Summary of Con(text) items

# . summarize Mot1 Mot2 Mot3 Mot4 Mot5 Mot6 Mot7 Mot8 Mot9 Mot10 Mot11 Mot12 Mot13 Mot14 Mot15 Mot16

Variable	Obs.	Mean	Std. Dev.	Min	Max
Mot1	49	3.408163	2.080849	1	7
Mot2	49	3.122449	2.127525	1	7
Mot3	49	2.795918	1.80254	1	7
Mot4	49	3.265306	2.059283	1	7
Mot5	49	3.877551	2.16634	1	7
Mot6	49	3.693878	2.073685	1	7
Mot7	49	4.428571	2.254625	1	7
Mot8	49	5.265306	2.028706	1	7
Mot9	49	4.979592	1.853935	1	7
Mot10	49	5.673469	1.448962	1	7
Mot11	49	4.040816	2.327008	1	7
Mot12	49	5.265306	1.934075	1	7
Mot13	49	3.632653	2.157293	1	7
Mot14	49	3.816327	2.251606	1	7
Mot15	49	3.77551	2.143452	1	7
Mot16	49	4.061224	2.418748	1	7

Figure 64: Summary of Mot(ivation) items

#### . summarize Belief5 Belief27 Belief31 Belief32

Max	Min	Std. Dev.	Mean	l Obs	Variable
7	1	1.542758	2.510204	49	Belief5
7	1	1.702339	2.653061	49	Belief27
7	1	1.881028	2.591837	49	Belief31
7	1	1.525018	2.612245	1 49	Belief32

Figure 65: Summary of Norm items

**End of thesis**