

**Multiple levels of influence affecting the utilisation of adult
asthma services in the private sector in Khartoum**

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**I declare that this thesis is my own work and has not been submitted for the award
of a higher degree elsewhere**

Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in Khartoum

Abstract

Background

Asthma is the third most common cause of hospital visits in Sudan and globally affects more than 300 million people (WHO, 2007) (IUATLD, 2011, 2018). Sudan has a pluralistic health care system with a strong and varied private sector and a three-tiered public health sector (federal, state and district). Most asthma patients in Sudan seek asthma care in hospital emergency rooms or in the private sector. The main constraints of the asthma services in the public sector are lack of resources, lack of medical doctors in certain areas, inconsistent drug supplies and an absence of community involvement in health affairs (Ebrahim et al., 2017). While there has been research examining the low availability of asthma services in the public sector in Sudan (El Sony et al., 2013), very little is known about which asthma services are available in the private sector.

Objective

The goal of this thesis was to use a mixed method approach to understand the utilisation of adult asthma services in the private sector in Khartoum.

Design

The research design was constructed using an explanatory sequential mixed method Social Ecological approach (Creswell, 2013). This approach was used to examine the **Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in Khartoum** 2

influencing factors of asthma service utilisation in the private sector by considering the five nested, hierarchical levels: individual, familial/interpersonal, community, organisational, and policy/enabling environment. The quantitative research was conducted using a health facility survey of private hospitals, private chest clinics, and pharmacies, in order to describe the asthma services available. This was followed by qualitative research using in-depth interviews with asthma patients who use the private sector, to explore decision-making around facility use and asthma health care seeking behaviour in more detail.

Findings

The quantitative survey found low rates of spirometers and peak flow meters were available in private hospitals (28% and 33%, respectively). There was very little asthma-specific training for providers and little use of asthma treatment cards and registers. However, the qualitative interviews found that the quality of care in the private sector was viewed as better than in the public sector, with shorter waiting times and better hygiene levels. Patients sought frequent, short-term care at private facilities for acute attacks (predominately in hospital emergency rooms) rather than long-term management of their condition as outpatients. The severity of the disease and the major impact it had, particularly on younger adults' lives, was striking. Stigma and misconceptions about the disease by the community was expressed strongly particularly by younger women and altered how they sought care and how they interacted with people in their social network and beyond.

Conclusion

The Social Ecological approach facilitated an in depth understanding of the barriers and enablers of effective care. Effective asthma case management requires input at all levels of service provision: inclusive health policy and government commitment, high quality service delivery, an uninterrupted affordable drug supply, community involvement in care and patient empowerment. Encouraging stakeholders across the different levels of influence to implement this holistic model of asthma case management across both the public and private sector has the potential to lead to a reduction in emergency room admissions, less severe asthma attacks, a reduction in asthma related stigma and less fear of social rejection and concern for the patients.

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Chapter 1: Introduction

1.1 Project starting point

The initial catalyst of this research was my own personal observation, as a researcher, of the very high prevalence of severe asthma in Sudan and the impact it has on people's lives. People with asthma can live normal lives if their asthma is managed properly. In many low and middle-income countries, low awareness of the disease, health systems challenges and inaccessible asthma care are among the major factors that contribute towards poor management of asthma and can lead to dangerously increased severity of the disease (IUATLD, 2011). In Sudan, the inability to access asthma preventative drugs in the public sector and a lack of effective basic care results in asthma being mostly treated in hospital emergency rooms or in the private sector as opposed to primary care outpatient clinics in the public sector. There is very limited literature on asthma treatment in Sudan or the Arab region. Consequently, little is known about the factors affecting patient decision-making, if and where they seek treatment and the primary drivers or barriers to that decision within this region.

There has been research examining the low availability of asthma services in the public sector in Sudan (El Sony et al., 2013), but very little is known about which asthma services are available in the private sector. An editorial in the Sudan Journal of Public Health called for more research to be conducted that explores the private sector's role and potential in health delivery (Badr, 2010). This research aims to explore when, where and why patients seek asthma care in the private sector. In

particular, it identifies the importance of understanding the availability of private sector service provision to provide a context to understanding the patients' decision-making. In turn, these findings identify a potential impact for policy makers by providing a more informed picture of health utilisation in Khartoum and help improve linkages between the public and private health care systems. I adopted a Social Ecological approach to the research looking at asthma services from different perspectives (policy, health systems, community, family and individuals). The problem of high levels of asthma in Sudan has been documented with prevalence among Sudanese adults approaching 10% in many areas (Elamin et al., 2012) but there has been little research regarding the reasons why there are such high levels, how asthma patients interact with the different levels of the health system, how use of the private sector for asthma care differs to public sector use and what can be changed to improve the situation for those living with the disease.

1.2 Theoretical approach

Most successful public health programmes are based on an understanding of health behaviours and the contexts in which they occur (Glanz 2008). It is suggested no single factor or set of factors adequately account for a behaviour and that thinking beyond the individual can enhance knowledge and understanding of a health programme (Ammerman et al., 2002). The Social Ecological theory explores dynamic levels of influence such as personal /individual factors, interpersonal/familial factors and societal influence that continually interact to affect a health outcome. It encompasses the perspective of the individual, the interpersonal (social cultural

factors) and the broader organisational and policy environments (health system and health policy). This research will use Social Ecological theory, which is discussed more fully in chapter 2, to explore these interacting components to look at how and why asthma patients seek care in Khartoum. It will examine the interface of the social, cultural and economic environment of asthma patients, the physical environment of asthma services and asthma patients' individual characteristics and behaviours (Grundy & Annear, 2010).

1.3 Aims and objectives

Key research question: what are the main influences for the utilisation of private sector asthma treatment in Khartoum?

The aim of this research is to gain an understanding of the health-care-seeking behaviour of adult asthma patients who use the private sector in Khartoum to treat their illness.

Research objectives

Objective 1: To examine the provision of asthma diagnostic and treatment services available for adult patients in the private health sector, in Khartoum

Objective 2: To identify the factors that result in asthma patients choosing private health care providers for their treatment.

Objective 3: Explore how and why asthma patients make health care provider choices within the private sector

1.4 Non-communicable diseases in low and middle-income countries

In 2011, the United Nations General Assembly held a high-level meeting of policy makers for the first time to address the prevention and control of Non Communicable Diseases (NCDs), with a particular focus on the challenges faced by low and middle-income countries (LMIC)¹ (Alleyne et al., 2010). It is estimated that 63% of all deaths worldwide are due to NCDs, and this is expected to rise. By 2030, NCDs are projected to cause nearly five times as many deaths as communicable diseases worldwide (Assembly, 2011).

There are four main categories of NCDs: cardiovascular disease, cancer, respiratory disease, and diabetes. These are all chronic, long-term conditions. It is estimated that 80% of all NCD deaths occur in low- and middle-income countries (WHO, 2013). However, focusing on death rates alone can mean that respiratory diseases such as asthma are neglected in terms of global funding and advocacy, there needs to be a

¹ For the current 2017 fiscal year, low-income economies are defined as those with a GNI per capita, calculated using the [World Bank Atlas method](#), of \$1,025 or less in 2015; lower middle-income economies are those with a Gross national income (GNI) per capita between \$1,026 and \$4,035; upper middle-income economies are those with a GNI per capita between \$4,036 and \$12,475; high-income economies are those with a GNI per capita of \$12,476 or more (Bank, 2017)

focus on quality of life and improving morbidity. The global push on shared behavioural interventions proposed to address NCDs, such as improved diets and exercise, will have little effect on controlling asthma (Pearce et al., 2013). Respiratory diseases, in particular asthma, were also found to have a strong inverse association with wealth and education which contrasts with other NCDs such as diabetes and heart disease (Hosseinpoor et al., 2012).

1.5 Asthma, its symptoms and prevalence

Asthma is a chronic, non-communicable respiratory disease of the lungs, in which inflammation leads to wheezing, breathlessness, and coughing. It can cause severe disability, and if left untreated, can result in death (Desalu et al., 2011). It can develop at any age, but symptoms usually start in childhood. The causes of asthma are not well understood; asthma attacks can be triggered by an allergic reaction, but this is not the case for all. Asthma often runs in families, but non-genetic factors such as air pollution and smoking also play a key causal role (IUATLD, 2011).

The prevalence of asthma has increased dramatically worldwide over the last 20 years and currently affects 300 million people (Ait-Khaled et al., 2007). It is estimated that 180,000 people die every year of asthma related complications, globally (Bousquet et al., 2003). There is no known cure but the disease can be controlled, and its severity lessened by regular use of inhaled steroids. It affects both sexes of all ages. In children, significantly more boys are affected than girls, but by adolescence, this difference has evened out, and by adulthood, more women than men suffer

from the disease (Azza et al., 2011). The reasons for this are not widely understood, but it is thought that pollution (especially indoor pollution) may be a factor.

Asthma is a disease found in both developed and low and middle-income countries (LMICs). However, prevalence, severity, and mortality due to asthma is rising much more rapidly in LMICs compared to high income countries (Bousquet et al., 2005). Correct diagnosis is a key challenge in asthma care. There are no blood or urine point-of-care tests that can accurately diagnose the disease. Diagnosis involves taking a detailed history, a physical examination, and lung function tests such as spirometry or the use of peak flow meters (Adeloye et al., 2013). However, in many LMICs clinics and hospitals, spirometers are not available as they are expensive and require specific training to use. Whilst effective medicines do exist (a combination of inhaled steroids and bronchodilators), these are often not prescribed or available. A study by the World Health Organisation found that the three drugs it recommended for asthma treatment were rarely available in LMICs and especially rarely available in the public sector. When they were available in these settings, the costs were extremely high (Lessing et al., 2013).

1.6 Barriers to successful asthma management

Eight key barriers to successful asthma management in low and middle-income countries have been identified (Bousquet et al., 2005). These are:

1. Economic and generic barriers; the broader social factors of health that affect health care seeking for asthma, such as poverty, poor education, poor sanitation, and poor infrastructure.
2. Cultural barriers; these have a larger impact in areas of multiple languages and religious beliefs (Enarson & Ait-Khaled, 1999).
3. Environmental barriers including tobacco smoking, indoor and outdoor air pollution, and occupational exposure.
4. Asthma Drug and diagnostic device shortages, which is considered a major barrier particularly in LMICs (Sterckx, 2004).
5. Traditional medicine which is very commonly used in many countries and is often the first point of care for patients with asthma and can be used alone or in combination with modern medicine.
6. Differences in health care systems: there are large differences in the equity of access to health facilities in many countries and these are much more pronounced in LMICs.
7. Gaps and relevance of guidelines for low and middle-income countries; often existing guidelines for asthma care do not take into account issues faced by LMICs such as a lack of available drugs, transport issues travelling to asthma facilities, specialised training for asthma care providers or affordability of the asthma services (Ait-Khaled et al., 2006).
8. Lack of symptom based guidelines: this is a barrier for health professionals when diagnosing asthma and prescribing care. (Bousquet et al., 2005)

These barriers to effective asthma care do exist throughout the world but are much more pronounced in LMICs (Pearce et al., 2013). Asthma used to be considered as a condition that predominately affected those in the western world (Beasley, 2011), however, this has changed and the majority of those living with the disease now are located in low and middle-income countries (Ait-Khaled et al., 2007)

1.7 Asthma in low and middle-income countries

Respiratory diseases now account for 17.4% of all deaths in sub-Saharan Africa (Bousquet et al., 2003). This figure is expected to rise due to increasing levels of urbanisation, outdoor and indoor air pollution, and tobacco smoking. In 1990, there were 74.4 million reported cases of asthma in Africa. This figure rose to 94.8 million cases in 2000 and 119.3 million in 2010 (Adeloye et al., 2013). However, due to low levels of accurate diagnosis, the true prevalence of the disease is expected to be much higher. It is estimated that the number of cases will continue to increase and reach 400 million by 2025 (IUATLD, 2011).

Asthma symptoms are well recognised in many low and middle-income countries, but the causes and related treatment options are not fully understood and are often treated by traditional methods (Musafiri et al., 2011). For example, in Tanzania, traditional healers believe that asthma is caused by ingestion of amniotic fluid from birth (83%), God (75%), or inherited from parents (73%) (Semali & Masawe, 1985). In Ethiopia, the treatment for asthma is varied and ranges from eating raw beaten eggs

to smoking dry elephant dung (Teklu, 1989). In Sudan, the main traditional asthma treatment is the use of Nigella seeds (Koshak et al., 2017)

The majority of people living with asthma in LMICs have very limited access to essential prevention and treatment (Lessing et al., 2013). There is a high financial burden on the person living with the disease, on their families, and on the health-care system (Ait-Khaled et al., 2007). Inadequate treatment coupled with high financial healthcare costs often results in high levels of disability, absenteeism, and increased risk of poverty. If the disease is left untreated, it can become much more severe and result in hospitalisation, or in some cases death. Severe adverse outcomes of asthma, such as death and hospitalisation, disproportionately affect the poor compared to higher socioeconomic groups (Ait-Khaled et al., 2000). The total cost of asthma treatment and care is estimated to be at least USD \$20 billion annually in LMICs (Ait-Khaled et al., 2007). Due to the fact that many cases do not receive adequate diagnosis and treatment, the condition worsens and costs escalate as people visit hospital emergency rooms for urgent treatment (Ait-Khaled et al., 2007).

In addition to a chronic shortage of asthma drugs in LMICs, there is also the issue of weak health care systems that are unable to support the patient. Most LMICs do not have standard protocols for assessing and managing chronic NCDs such as asthma (Ait-Khaled et al., 2001). Other key obstacles to asthma care are the availability of equipment, poor chronic care education of health workers, weak asthma case

notification and recording systems, and the issues of implementing long term care in a poorly functioning health care system (Ait-Khaled et al., 2001). A recent study of asthma care in the public sector in Nigeria found that most of the hospitals surveyed lacked basic infrastructure for asthma care, and only one third had diagnostics tests such as peak flow meters or spirometers (Desalu et al., 2011). In addition to weak health care system support for asthma patients, it has been shown that there are sociocultural misconceptions attached to the disease and to the use of inhaled steroids, and that these have a significant effect on adherence to treatment (Adeloye et al., 2013). One study in Yemen found that patients preferred tablets or injectables to inhalers (Schultz, 2002), although the study did not explore the reasons for this.

1.8 Asthma as a leading cause of hospital emergency room visits

Untreated asthma and poor management of the disease can lead to frequent visits to hospital emergency rooms (Bilal et al., 2016). This phenomenon is seen across the world in both high income and LMICs but is thought to be more frequent in LMICs where there is weak asthma provision in the public sector (IUATLD, 2011, 2018).

There are many factors that lead patients to seek care in the emergency room including asthma severity, incorrect perceptions of the disease and its medication, lack of an asthma treatment plan, over-reliance on short acting bronchodilators, changes in weather and pollution, and education and socioeconomic levels (Hamdan et al., 2012). A study in Saudi Arabia found that the main reasons for asthma patients visiting the emergency room were to obtain oxygen or a short-term bronchodilator.

These were viewed by many patients as the recommended therapies for acute

asthma, and many depend on the emergency room for asthma management (Hamdan et al., 2012). Avoiding crisis care of acute asthma by long-term management and reducing the use of emergency rooms for acute asthma treatment are major goals of asthma management, as detailed in the Global Strategy for Asthma Management and Prevention (Beasley, 2011).

1.9 Asthma in Sudan – a growing problem

Asthma is a major health concern in Sudan and there is an estimated overall prevalence of 8.7% of the population (global prevalence is 4.3%) (WHO, 2007).

Asthma is ranked as the third most common cause of hospitalisation in the country, following pneumonia and malaria (excluding maternity and deliveries) (El Sony et al., 2013). There was a striking rise in the number of emergency room visits by asthmatics between 1998 and 2004, increasing from 20,000 to 106,000 (IUATLD, 2011). While asthma is a concern for the Ministry of Health in Sudan, it is not listed as a public health priority, and in the public health sector there are very few peak flow meters (which measure a person's ability to breathe out air) for diagnosis, few drugs available, and few staff trained in asthma management (El Sony et al., 2013). Many health professionals working in public or private sectors are not trained in tackling chronic asthma or long-term management of the disease (Ait-Khaled et al., 2007). This combination of factors leads asthma patients to seek care in the private sector. In 1991 user fees for consultations, drug and inpatient hospital visits were introduced in the public health sector and it is estimated that total health out of pocket expenditure across all health conditions is larger than total government

health spending (EMRO, 2006). Research on asthma management in Sudan, conducted in 2003, found that 95% of patients paid the full cost of their asthma medicines; less than 2% of them received regular treatment from a single facility, and the patients had no knowledge of their asthma management plan (IUATLD, 2011). In a country where the daily wage of the lowest paid, unskilled government worker is USD\$2.20 per day, the cost of one day of hospitalisation for asthma is USD\$79.60 and patients are also responsible for the cost of medicines, and other additional costs (IUATLD, 2011). These high costs of health care and medication often result in asthma patients self-managing their condition and only seeking care when they are extremely ill.

A situational analysis of asthma patients using public health facilities in Khartoum and Gezira (Ait-Khaled et al., 2007) found that cough, wheezing, and breathlessness were the most common reported symptoms: however, the severity of the symptoms or severity of the disease were rarely noted. Peak flow meters were not available and airflow impairment was not assessed. Inhaled corticosteroids are essential for decreasing severe asthma attacks and for managing the disease long term (Ait-Khaled et al., 2006).

However, they are often not available in the public sector and expensive in the private sector. Most patients were treated with a combination of antibiotics, oxygen, oral steroids, and salbutamol (a bronchodilator). Management of the condition focused on treating the acute asthma attack with no long-term disease management. This leads to a high frequency of unplanned visits to health services, and hospital emergency rooms in particular.

A recent study of asthmatic patients at public hospitals in Khartoum, found that many have a low level of knowledge of their disease, are reluctant to accept the diagnosis, and prefer to consider the disease as an allergy (Merghani et al., 2012). 46% of patients interviewed did not use preventers regularly when prescribed, and most used inhalers only for the treatment of asthmatic attacks as and when they occurred (Merghani et al., 2012). A study in Khartoum in 2014, found that a quarter of asthmatics studied were not on inhaler therapy at all, and more than one third were not on steroid inhalers (Imad & Yasir, 2015). The researchers also observed very poor inhaler techniques in the study group. This was consistent with a study at the main respiratory hospital in Khartoum, where 82% of patients were found to have poor inhaler technique (Abdelhamid et al., 2008). This emphasises the importance of patient education and physician training.

1.91 A pluralistic health care system in Sudan

Sudan has a three-tiered health care system: federal, state, and local/district. The federal system is mainly responsible for setting national policy, overall monitoring and evaluation, supervision, and training. The state-level formulates its own policy and plans, according to federal guidelines, and then funds these plans through taxation and fee for service. The local-level implements the state plans using funds devolved from the state budgets and from user fees, based on the primary health care approach. A report by Save the Children suggested that decentralisation has moved the responsibility of public health care provision to the state level authorities, but this has not been accompanied by increased resources to the states to manage the cost of providing the services (SCF, 2005).

Partly as a result of low confidence in the public health sector in Sudan, a pluralistic health system has grown and health care is provided by both the public and private sector (Pantuliano et al., 2011). The government levels of funding for the public health sector is low at 6% of the GDP, well below the 9% recommended by the World Health Organisation (WHO), and there is high out-of-pocket expenditure by individuals, estimated to be above 60% of monthly salary (WHO, 2011). There are policies to exempt user fees for vulnerable groups but in practice these exemptions are not often applied (Ebrahim et al., 2017). Primary health care services have struggled to keep up with the increasing population of the country. Up to the 1990s, public health services were provided for free but now operate on a fee for service basis and is one suggested reason for the large growth in private clinics and hospitals (Awad et al., 2006). The private sector includes 'not for profit' and 'market based/for profit', and has expanded rapidly in the last 10 years (Eltilib et al., 2010). The Government has strongly encouraged the private sector to provide services in urban areas, and there has been a rapid increase in private health facilities which are located throughout the cities in Sudan, but predominately in the Khartoum urban area (Pantuliano et al., 2011).

For these reasons, I have focused my research on the Khartoum urban area. The pluralistic nature of the health system in Khartoum presents an opportunity within Sudan to use a Social Ecological approach to examine the dynamic relationship between asthma patient decision-making, Socio-Cultural factors and health service provision.

1.92 Outline of the thesis

Chapter One has outlined the research starting point and provided a brief introduction to the issues surrounding non-communicable diseases in low and middle-income countries and how those issues relate to asthma in particular. It has sought to highlight the key barriers to asthma care and how these issues are exacerbated in LMICs. It has given an overview of the health care system in Sudan with a focus on Khartoum and how the low provision of asthma services in the public sector has led to a surge in the use of the private sector.

Chapter Two briefly outlines the methodology for the literature review, theories regarding individuals' health seeking pathways (if and when to seek care) and theories regarding the health system of health care utilisation (where to seek care within complex health care systems) and the Socio-Cultural factors affecting decision-making. The chapter then focuses on pluralistic health care systems in more detail and the changing ways that health services are accessed in LMICs. Finally, the chapter links the multiple levels of influence (health policy, health system, community, family and individual) that affect health care decision-making for asthma care.

Chapter Three begins with an overview of the theoretical underpinnings of the research methodology including the rationale for a mixed methods approach and sequential design. It then outlines the methodology conducted in this research

project with a description of the quantitative and qualitative methods that were used.

Chapter four presents the findings of the quantitative and qualitative research. It is structured according to the Analytical Framework (page 77) and the key models of access to health services, the pathway to care and the Social Ecological model of the multiple levels that influence health care behaviour (Levesque et al., 2013; Peters et al., 2008; Shahabuddin et al., 2017). It opens with the results of the quantitative health facility survey, then the qualitative research with asthma patients is presented, starting with a focus on the access to services from the patients' perspective leading to the discussions surrounding the process and pathway to health care.

Chapter 5 aims to provide a discussion of the different interpretations of the findings of the study using a Social Ecological approach and the implications for asthma care and the provision of asthma services. It aims to provide an understanding of how asthma patients engage with different health systems, what the actual or perceived barriers are to accessing asthma care, and how the different levels of health care influence asthma patient behaviour.

Chapter 6 presents the main conclusions of the study including the key findings, the contribution to knowledge, recommendations for further research and potential policy implications.

Chapter 2: Literature review

2.1 Chapter summary

This chapter will consider the three main areas of literature that inform our understanding of the choices that are made in health care seeking (symptoms, perceived threat of disease and perceived effectiveness of care) and health care utilisation (health system factors, individual factors and sociocultural factors). There is little literature regarding health care seeking by asthma patients, so I have included broader literature on the different levels of influence affecting health care seeking. This chapter will provide a review of the literature on the range of factors affecting the choice of provider by identifying the key theories on health-care utilisation (theories taking a health systems perspective) and health-seeking behaviour (theories taking an individual perspective). It then focuses on the literature which applies these models to the type of health provider and complex health care system that occur in low and middle-income countries. It moves on to consider the disease specific literature regarding access to health care and choice of provider for asthma care in low and middle-income countries. The literature search strategy is set out below and focuses primarily on asthma care provision in adults in low and middle-income countries, including relevant research articles on asthma in Sudan.

2.2 An overview of the theoretical approach

Asthma is a major health concern in Sudan and the provision of asthma care and services in the country is complicated (El Sony et al., 2013). Sudan has, like many

other countries, a complex health system. It has transitioned from a formerly centralised public administrative structure to a more decentralised and market orientated one as in other similar countries, such as Ghana and Tanzania (Grundy & Annear, 2010). Understanding health seeking behaviours and the causes of those behaviours within the context of complex health systems can help to understand which interventions result in improved health outcomes and where policy makers can focus their resources (Shaikh & Hatcher, 2005). Asthma is a disease that is both acute (life threatening attacks) and chronic requiring long-term care. This means that in higher income countries, the health system is accessed at multiple levels and for different purposes; emergency care for acute attacks while long term management of the disease is often managed at outpatient clinics. Understanding the supply and demand factors of the health system and the health seeking behaviour of patients could lead to improvements in service delivery and ultimately lead to better health outcomes. The diagram below was used as a framework to guide this research and builds on Social Ecological theory (figure 1) (Shahabuddin et al., 2017). It outlines the relationship between multiple levels of influence that exists between individuals, households, health institutions, and the wider sociocultural environment, and the subsequent influence these have on decision-making and on understanding health-care utilisation behaviours. This research looks at the interaction between these levels of influence: individual, interpersonal, societal, organisational and policy. Table 1 describes each of these levels and how they related to health care seeking and provision.

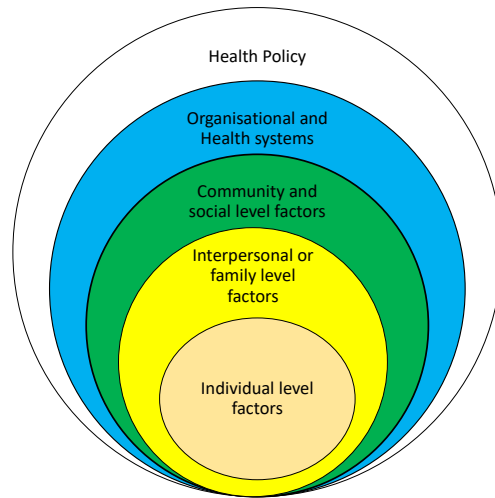


Figure 1: A Social Ecological approach: Multiple levels of influence in health care behaviour (Shahabuddin et al., 2017)

Table 1: A Description of Social Ecological Model (SEM) Levels (UNICEF, 2014)

SEM Level	Description
Individual	<ul style="list-style-type: none"> Characteristics of an individual that influence behaviour change, including knowledge, attitudes, behaviour, self-efficacy, developmental history, gender, age, religious identity, racial/ethnic/caste identity, sexual orientation, socio-economic status, financial resources, values, goals, expectations, literacy, stigma, and others.
Interpersonal	<ul style="list-style-type: none"> Formal (and informal) social networks and social support systems that can influence individual behaviours, including family, friends, peers, co-workers, religious networks, customs or traditions.
Community	<ul style="list-style-type: none"> Relationships among organizations, institutions, and informational networks within defined boundaries, including the built environment (e.g., parks), village associations, community leaders, businesses, and transportation.

Organizational	. Organizations or social institutions with rules and regulations for operations that affect how, or how well, for example, health services are provided to an individual or group; schools that include health in the curriculum.
Policy/Enabling Environment	. Local, state, national and global laws and policies, including policies regarding the allocation of resources for health and access to healthcare services, restrictive policies (e.g., high fees or taxes for health services), or lack of policies that require childhood immunizations.

2. 3 Literature review search strategy

The primary search engines used as starting points for the review were PubMed and Google Scholar which are two of the most commonly used search engines for Global Public health. I also searched the following websites for relevant non peer-reviewed literature such as policy documents, meeting reports, working papers and conference findings: World Health Organisation, DFID, GINA, IUATLD, the World Bank, Save the Children, Global Asthma Network, and Sudan Ministry of Health.

The search terms used are in table 2 below:

Table 2: Search terms

Asthma	Stigma
Non communicable diseases	Choice of provider
Health seeking	Access
Health care utilisation	Barriers to access
Private provider	Pathways to care
Private sector	Health care system
Low and middle-income Country	Burden of disease
Sudan	Adults

The terms in the first column were always used in combination with one or more terms from the second. Only English-language articles were reviewed. The time period selected was 1995 to 2017. A search of both databases for articles that included the words 'asthma' and 'Developing countries' revealed that more than 85% of articles on this central theme had been written since 1995. Hence this date was selected as the cut-off date for the literature search.

The methodology used to search and select the peer reviewed journal articles is summarised in Table 3. The abstracts of all selected articles were reviewed, and those that addressed only the medical aspects of asthma without reviewing the disease in the context of the health care system, were excluded for the purpose of this thesis. Figure 2 details the number of papers identified, screened and reviewed. Articles reviewing drug-dosage and diagnostic technical innovations in the developed world or that focused fully on asthma in children were also excluded as they were not directly relevant to the research question.

Full texts of relevant articles were obtained, and the bibliographies of those that were most pertinent to the theme were also examined, and with all relevant linked articles reviewed. All titles and keywords in any journal issue from which an article had been identified, were also scanned to identify other useful documents on the same theme. Table 3 summarises the key search terms used and the number of articles each search produced. When a search yielded more than 100 articles, additional search terms were added to bring focus and narrow the field. Table 1 also

describes the main search engines used and the inclusion and exclusion criteria for selecting which studies to include in the literature review. The focus of the review was factors affecting the choice of provider.

Table 3: Literature search strategy

Search Terms:					
Key word	Key word(s)	Number of papers found	Additional key words (added when search number was over 100)	Number of papers found	Number of papers retrieved after applying inclusion/exclusion criteria
Asthma AND	Developing countr*	573	AND adults	216	28
Asthma AND	Stigma	66			2
Asthma AND	Health seeking	251	AND adults	135	11
Asthma AND	Health care utilisation	143	AND adults	79	4
Asthma AND	Private providers	53			5
Asthma AND	Sudan	30			13
Asthma AND	Choice of provider	11			1
Asthma AND	Access	1295	AND developing countr*	27	1
Asthma AND	Barriers to access	150	AND adults	68	1
Asthma AND	Pathway to care	319	AND adults	71	7
Asthma AND	Burden of disease	1528	AND developing countr*	55	8
Data Bases searched:					
PubMed, Google Scholar					

<p>Part of Journals searched:</p> <p>Keywords in abstract and title</p>
<p>Years of Search:</p> <p>1995 – date</p>
<p>Language:</p> <p>English</p>
<p>Types of studies included:</p> <p>All types of studies: mixed methods, qualitative, quantitative and policy briefs</p>
<p><u>Inclusion Criteria</u></p> <ul style="list-style-type: none"> • Study target audience characteristics related to patient-centered approaches to asthma health care seeking and treatment • Describe elements of health seeking, health care utilisation in particular in low and middle-income countries • Describe interventions for patient and family engagement in asthma care seeking • Use qualitative or quantitative research methods, including meta-analyses and literature reviews. • Describe theories related to asthma and health care system factors in low and middle-income countries • Are opinion or editorial pieces only if directly related to asthma access in low and middle-income countries • Articles published since 1995
<p><u>Exclusion criteria:</u></p> <ul style="list-style-type: none"> • Focus on only clinical aspects of asthma • Focus on only asthma care in developed countries without addressing health seeking behaviour • Focus on only children’s asthma care • Focus on only specific new asthma drug/ diagnostic technology • Non-English • Published earlier than 1995

PRISMA Flow Diagram

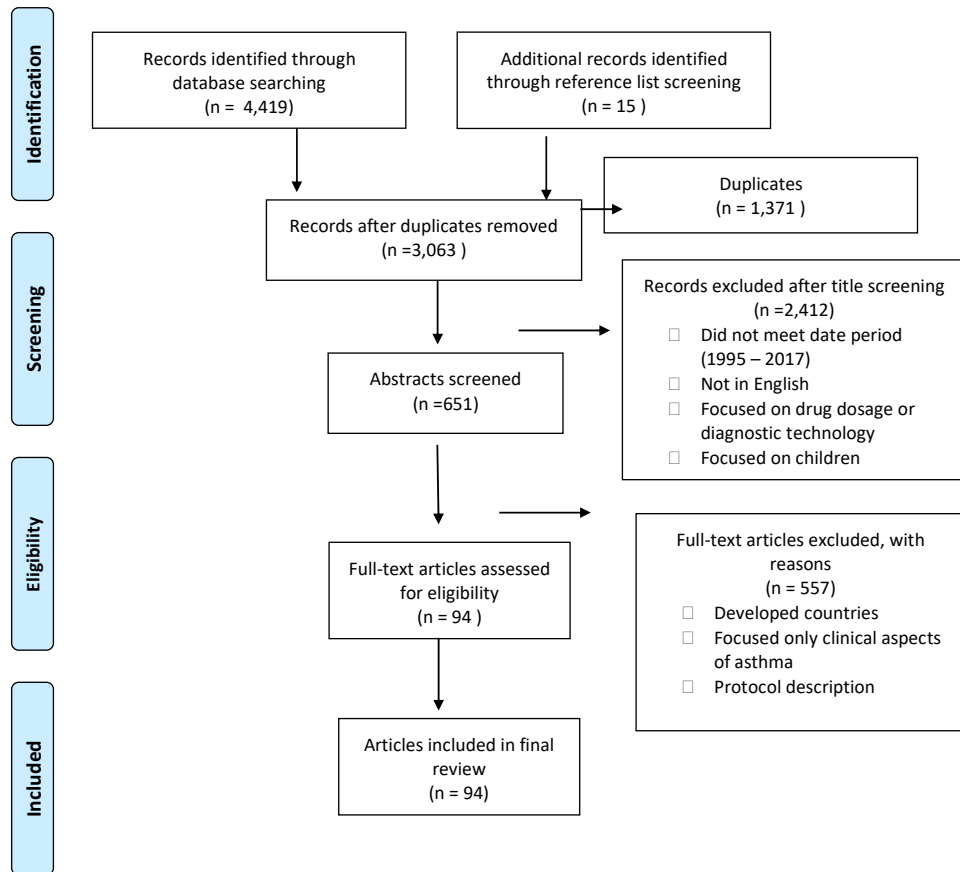


Figure 2: A Flow diagram detailing the literature search process

The majority of the articles identified through the literature review were policy analysis and theoretical discussions regarding access to services. Where the article did present an intervention that was evaluated, I applied the GRADE principles of

quality (Badger et al., 2000). The GRADE approach (Grading of Recommendations, Assessment, Development and Evaluation) is a system for rating the quality of evidence adopted by WHO and many other organisations. It ranks the evidence from high quality (usually randomised controlled trials) to low quality (some observation studies) (Guyatt et al., 2011). I took an inclusive approach so that even those articles that scored lower quality were still useful for the discussions that they presented. This inclusive approach meant that I did not exclude any journal articles based only on quality but applied the inclusion criteria outlined in table 3. I took a thematic analysis approach to the literature review due to the fact that the literature on this topic is so limited. It was hoped that reviewing different styles of interventions could highlight potential areas for future research and possible experimental solutions for the issues found. Table 4 below sets out the number and types of articles and studies found during the literature search process.

Annex A summarises the selected journal articles and gives details of the author, date of study, location, research question, design of study and key finding.

Table 4: literature search findings

Thematic Area	Empirical	Policy Brief/ Commentary	Review	TOTAL
Asthma	12	14	5	31
Access	5	5	15	25
Private	6	16	7	29
Respiratory disease	1	3	1	5
Non Communicable Diseases	0	3	1	4
TOTAL	24	41	29	94

The articles were reviewed under the headings: summary/synthesis, comparison

/critique as set out in Table 5.

Table 5: literature review criteria

Summary and Synthesis	Comparison and Critique ²
<ul style="list-style-type: none"> ▪ What is known about the immediate areas of this research field? ▪ What are the key arguments, key characters, key concepts, key figures? ▪ What are the existing debates/theories within this study? ▪ What kind of methodologies were used? 	<ul style="list-style-type: none"> ▪ How does the study relate to others? What is new, different, or controversial about this study? What views need to be further tested? ▪ Is the evidence comprehensive or limited, inconclusive, contradicting? ▪ Did the research designs or methods seem satisfactory/unsatisfactory?

² Table adapted from: <http://pwr.la.psu.edu/resources/graduate-writing-center/handouts-1/Literature%20Reviews%20Fall%202010.pdf>

Using a thematic analysis method, the literature that met the inclusion selection criteria (table 3) were organised based on key themes (Badger et al., 2000; Carolina, 2017; Philbrook, 2017). The organisation of the papers was done firstly by title and key word search, then the abstract was reviewed for relevance to the thesis topic and then the whole paper reviewed. I divided the papers into groups of similar themes (access, asthma care, private sector use, respiratory diseases and non communicable diseases in developing countries) and into types of paper (empirical, policy brief and review) as detailed in table 4. Summary notes were written on each paper in each category and then compared and contrasted. The reference lists of each paper were also reviewed for other potential relevant papers that could be helpful in the review.

Summary of literature search findings:

The key empirical papers on asthma that were included in the review focused primarily on patient pathways in hospitals and looked at potential ways of altering this pathway away from a reliance of hospital emergency room care by strengthening human resources such as training pharmacists or strengthening outpatient clinics to provide education on inhaler use and better prescribing techniques (Hamdan et al., 2012; Schultz, 2002). A lack of health education regarding inhaler use and shortage of inhalers were found to be key factors influencing asthma services and pharmacists were identified as having a potential role in engaging patients and improving asthma outcomes (Abdelhamid et al., 2008; Bosnic-

Anticevich et al., 2014; Osman et al., 2012). The key papers on access focused on health seeking behaviour with women identified as having lower knowledge levels of disease (Kamel et al., 2003) and high levels of self-medication, both herbs and over the counter pharmaceuticals in urban Khartoum for both men and women (Awad et al., 2005; Awad et al., 2006). Service quality (communication, responsiveness of health staff) was found to positively influence patient satisfaction and influence where a patient would seek care (Andaleeb, 2001; Lule & Allwright, 2003). With regards to the private health sector use, the main papers focused on comparing the costs involved in seeking private or public health care and patients' perceptions of differing quality between the sectors and found that costs were similar for public and private sector use and no significant differences between socio economic groups accessing the different sectors (George et al., 1997; Ha et al., 2002). The empirical study on respiratory disease highlighted that smartphones were a reliable method of recording prevalence data when compared with standard paper surveys and this study was used to assist the design of the quantitative data collection component of my study (Ahmed et al., 2018).

Due to the limited availability of asthma health care utilisation research in Sudan, the literature review draws on theoretical health care utilisation and health seeking behaviour models. It begins with a critical review of the main models and their limitations for analysis of developing countries. The second section then reviews empirical investigations into pluralistic health care seeking. The final section narrows

to apply the models and a pluralistic health approach to asthma service provision and asthma care seeking.

The literature review findings were divided into three main areas:

1. The key theories of health care seeking and health care utilisation: grouped according to the Social Ecological approach layers of influence: pluralistic health care, health systems perspective, community/cultural perspective including stigma, beliefs, gender issues and individual perspective (section 2.4).
2. Research regarding private health care use (section 2.5).
3. Research applying theories and models of asthma care seeking and asthma service utilisation for patients in low and middle-income countries (section 2.6).

2.4 The key theories of health care seeking and health care utilisation

2.4.1 Understanding health care use within pluralistic health care systems

Health care in almost all countries is provided within a pluralistic health care system and, consequently, patients face a large number of choices when seeking care (Horton & Clark, 2016). In order to understand why people choose one health provider over another and if, when and where to seek care, it is helpful to look at the theories of health-care utilisation and literature on health-seeking behaviour theory. Health-care utilisation studies take a health systems perspective and focus on the process of health-care utilisation, factors affecting the choice of provider, and

understanding the barriers to access. A broad definition of health-seeking behaviour is: 'when and where individuals seek help for an illness' (Lule & Allwright, 2003).

Health-seeking behaviour studies focus on an individual's perceptions of illness and health beliefs. Health care utilisation studies focus on the endpoint - the theoretical utilisation of the formal or informal health care system while the health seeking behaviour studies focus on the theoretical process of an individual seeking care.

2.4.2 The health system perspective:

The choice of health care provider is a complex one, and it is driven by both supply-side and demand-side barriers. Demand-side barriers are factors that influence the ability to use services; supply-side barriers are factors that hinder service uptake (Jacobs et al., 2012). Supply-side barriers include poor quality of staff skills, low availability of supplies (drugs and equipment), inadequate treatment protocols, and poor health facility buildings and infrastructure (Ensor & Cooper, 2004). These tend to be the focus of most of the health policy interventions, and where the majority of funding is focused but usually exclude the social and individual health seeking factors such as stigma and traditional beliefs that also affect provider choice.

Health-care utilisation theory takes a health-care system perspective and examines the utilisation of the system through the lens of service provision. Kroeger's model of health-care utilisation (Kroeger, 1983) and Andersen's Behavioural Theory of Health care use (Andersen & Newman, 2005)(Annex E), for example, seek to understand access to health services. They show how predisposing factors (such as

demographics, social structures and health beliefs) are interrelated with enabling factors (such as income, insurance, and availability of services).

The literature regarding predisposing variables or factors and enabling factors including barriers to accessing health services and the models that demonstrate this theory for the most part focus on health care system factors (Levesque et al., 2013). The main approach covered by health care utilisation models is the identification of supply and demand factors. However, it is proposed that these factors should be viewed as interlinked with each other. It is suggested in the literature that ignoring socio - cultural factors or socio-demographic approaches can lead community interventions to fail (MacKian, 2003).

Access to health care services is a complex concept that involves an adequate supply of services and the ability of a population to utilise these services (Gulliford et al., 2002). Utilisation is often used as a proxy of access; realised access being more measurable than potential access (Levesque et al., 2013). Access in terms of utilisation depends on a number of variables including affordability, accessibility, and acceptability of services (Peters et al., 2008).

Health-care utilisation models can give an insight as to why people choose one health provider over another and demonstrate that health service utilisation and access to services is a complicated decision-making process (Lavy et al., 1994). It is

also important to include distance and economic factors as key decision-making components in determining which health provider to access (Good, 1987). Four main dimensions of access to health care are identified as follows:

1. Geographic accessibility - physical distances or travel time to health facility or to pharmacies (Hjortsberg & Mwikisa, 2002).
2. Availability – the right services available for those who need them, appropriate opening hours, appropriate health workers and supplies needed and acceptable waiting times (Hanson (2003).
3. Financial accessibility – the relationship between price of services and the willingness and ability of users to pay for the services. This is also known as affordability and includes direct, indirect and opportunity costs (James et al., 2006).
4. Acceptability – the services and health providers meet the social and cultural needs to users and communities. This includes gender barriers to access, health workers’ behaviour, excessive bureaucracy and culturally sensitive communication (Andaleeb, 2001).

These four As of access - availability, accessibility, affordability, acceptability are illustrated in more detail in Figure 3 (Peters et al., 2008). In this model, quality of care is at the centre of all four dimensions of access, as it is viewed as an important component of each dimension. The dimensions outside the circle are the predisposing factors such as age, gender, wealth, and the environment in which the service user lives. These factors cannot be altered by health policy and interventions,

but their effects can be reduced or alleviated (Bates, Fenton, Gruber, Laloo, Medina Lara, et al., 2004).

Health care utilisation studies have often used patient surveys to investigate community characteristics in helping understand barriers to access (Guthmann et al., 2008; Sharma & Vong-Ek, 2009; Uthman, 2009). One study in South America used the Argentinean National Risk Factor Survey data to explore the interrelation of components in the Andersen Model (Jahangir et al., 2012). This model suggests that seeking health care is based on predisposing characteristics of the individual, enabling resources and need (Tomison, 2013). Jahangir et al found that the Health Care Utilisation theory holds true in that context, with increasing age and a perception of having poor health affecting acceptability are the largest impacts on utilisation. A study in Ecuador applied the Andersen model to the 2004 National Demographic and Maternal Health Survey (López-Cevallos & Chi, 2009). It also found that perceived need was a significant factor in health-care utilisation, as was economic status and indigenous ethnicity. These studies are useful in providing an overview of providers and patterns of facility use, but do not tend to identify the underlying decision-making of facility choice (Hausmann-Muela, Ribera, & Nyamongo, 2003).

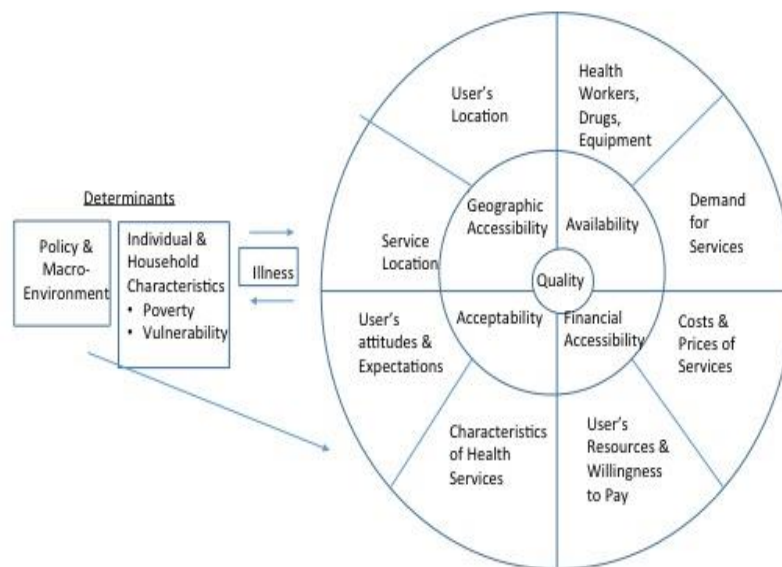


Figure 3: Model for assessing access to health services (Peters et al., 2008)

Many of these models were constructed with developed country contexts in mind and thus they often do not adequately account for situations in which there is a plurality in health care options. Given the plurality in healthcare systems in LMIC many of the models outlined above fail to adequately describe or predict health care utilisation in these contexts.

2.4.3 The cultural and community perspective

Studies on health-seeking behaviour have shown that obtaining and maintaining good health is not a question of simply offering good services or improving biomedical knowledge (Shaikh, 2008). It is a combination of physical, social, economic, cultural, and political factors that all play a part (Bates, Fenton, Gruber,

Laloo, Medina Lara, et al., 2004). Socio-Cultural theory stems from educational

psychology and highlights that behaviour and learning are social processes and that understanding the interaction between people and the culture in which they live is key to understanding behaviour (Bosnic-Anticevich et al., 2014). Demand-side barriers to seeking care are also often referred to as social and cultural barriers (STOPTB, 2005). These include a lack of health knowledge, low recognition of certain conditions as a priority, stigma of a disease, gender-related barriers to access, lack of assertiveness and low self-esteem, adopting traditional practices or beliefs, poor household cash flow and the opportunity costs of accessing services (Jacobs et al., 2012). A lack of quality, public sector services available nearby dictates that patients will need to travel to obtain health care. This means that they have to stop work, and/or find childcare cover, in addition to the increased treatment costs. In some cultures, including Sudan, women need to travel with a companion or chaperone, which leads to increased costs and adds a complexity to care-seeking (Ensor & Cooper, 2004). Social Norms Theory builds on the Socio-Cultural theory (Keller & Bauerle, 2009) and suggests that the environment and interpersonal influences (such as peers) can be more effective in behaviour change than a focus on the individual. Peer influences and normative beliefs have been seen to play a strong part of the decision-making regarding health seeking behaviour and accessing services. However, there are limitations to the theory; it relies on the message being well received and backed up by a health intervention. There is no point in a strong health education message (such as a drive to get people diagnosed) that changes social norms if there is no service available in the health system (such as a lack of

diagnostics equipment or trained personnel). This type of disconnect can lead to a surge in mistrust between communities and health professionals (LaMorte, 2016).

2.4.4 Stigma and Gender-related barriers to access

Certain infectious diseases such as tuberculosis (TB) and HIV are known to be associated with high levels of stigma. This stigma can lead to a fear of social exclusion, loss of employment and income, and poor marriage prospects (STOPTB, 2005). This fear can lead to denial of the condition, and subsequently a delay in seeking health care. Stigma and negative staff attitudes have a more deleterious effect on women and can impact on if, when and where they seek care (Bates, Fenton, Gruber, Lalloo, Lara, et al., 2004). Women tend to worry about social rejection (from husbands, in laws and community in general) more than men and in many countries, have to overcome more barriers to accessing care (such as having less use of household resources, less decision making power and care providing responsibilities are viewed as a priority (STOPTB, 2005). In poor countries, women often access health services less than men (Uplekar et al., 2001). Gender differences have been shown to be more pronounced in the Arab region than in other areas (Kronfol, 2012). It was found that in the region, women face more barriers in accessing health care services compared to men. The barriers highlighted were lower levels of understanding of their disease/condition, less access to household finances, the need for a companion or chaperone, the social expectation to be seen by a female health practitioner, have less decision-making power, and women believed their disease had greater consequences for their family and were more affected by

the social stigma of the condition (Kamel et al., 2003). One study in India, found that women of marriageable age (15 to 24 years) are far more likely to avoid the public health sector and access private care (George et al., 1997). The main factors highlighted for this preference for private care were proximity, convenient timings, cordiality and confidentiality. It was also suggested that public facilities were highly associated with family planning services and therefore there was stigma to access services there (Uplekar et al., 2001). There are gender differences affecting the choice of provider from both the provider and patient side: provider bias; treating and diagnosing women differently to men and patient bias; women delaying seeking treatment, more likely to self-medicate and the non-acceptance of a long term diagnosis (Borgdorff et al., 2000).

2.4.5 Perceptions and beliefs

Some groups, particularly in populations which tend to have low socioeconomic status, have strongly held cultural and traditional beliefs about health which causes patients to seek traditional or spiritual healing before seeking modern medicine (STOPTB, 2005). This can lead to a delay in diagnosis and can result in increased costs (financial, time, and opportunity). Patients may also find that these informal traditional health providers are easier to access and are therefore relied on in preference to the formal health care system. In Africa, traditional healers far outnumber medical staff and are usually located close to communities. This makes them popular and relied upon by communities (MacKian, 2003). As well as being a

first point of health care seeking, traditional medicine is often used in parallel with modern medicine by patients with long-term conditions.

Traditional beliefs on how certain illnesses are detected or treated can affect the type of care sought. In Tanzania, there is a strongly held belief that moths and hot sun cause the symptoms of fever and convulsions, symptoms that are known to correspond with malaria. As the individuals do not view their symptoms to be malaria, they seek out traditional treatments such as elephant dung and herbal concoctions, despite often knowing that malaria is best treated at hospital (MacKian, 2003). The type of health care provider that is sought, whether traditional, public or private, differs according to the type of disease. For example, mothers are more likely to seek modern public health care help for diarrhoeal disease than respiratory infections for their children despite both being leading causes of death in young children (Iwelunmor et al., 2010). Fever in malaria is often poorly recognised by mothers as it usually occurs with other symptoms and so may be thought to be worms or another illness and so seek treatment from pharmacies or local healers (Lubanga et al., 1997).

Often, as a person starts to suffer from the symptoms of a disease, a low level of health knowledge can mean a delay in seeking health care. In LMICs, this, coupled with other priorities such as deadlines in harvesting or selling at markets, can mean that the symptoms are dismissed as unimportant (O'Donnell, 2007).

A Socio-Cultural approach could view any changes in health service use as arising purely from changes in society and not from changes in the availability of new services. In the case of asthma care in Sudan, there is likely to be little success in patient education if demand is increased but not matched by an increase in available services. It is proposed that a combination of physical, social, economic, cultural, and political factors all interact to play a part in health seeking behaviour (Bates, Fenton, Gruber, Laloo, Medina Lara, et al., 2004).

2.4.6 The individual's perspective:

“To begin to picture the resources and constraints which impinge on treatment, the way the actor experiences them, is to take a crucial step towards understanding why and how people do what they do” (Wallman & Baker, 1996) (page 678)

Over the last few decades, there has been much discussion on individual health seeking theories. The Health Belief Model (Annex E) was developed to help understand why people did or did not use preventative services but has now been applied more broadly to all health services (Glanz 2008; Rosenstock et al., 1988). More recent theories have been grouped together as the Reasoned Action Approach (RAA) (Annex E) (Fishbein & Ajzen, 2005; Noar & Head, 2014) and share a focus on behavioural intention being key to understanding health behaviour. These theories of health seeking are built upon the Health Belief Model and Theory of Planned Behaviour. These theories address motivation, attitudes and intentions but not

actual behaviour or behaviour change. They assume a direct link between intention and behaviour which is not always the case (Schwarzer, 2008). RAA intention theories focus on the initial motivation phase but there is a need, especially where service provision is weak, to understand health seeking behaviour where intentions are translated into action and why some barriers are more significant than others (Schwarzer, 2014).

Trans-theoretical theory also takes an individual's perspective but views behaviour change as a process or series of steps. People move through these steps not in a linear manner but may repeat and recycle the steps (Glanz 2008; Prochaska et al., 1992). This health care seeking behaviour approach focuses on an individual's perspective of illness and their knowledge and choices in response to illness and the resulting health care action they take (Levesque et al., 2013). These are often referred to as Pathway Theory and include the consequences of care seeking and focus primarily on an individual's attitudes and prior experience of seeking care as shown in Figure 4 below.

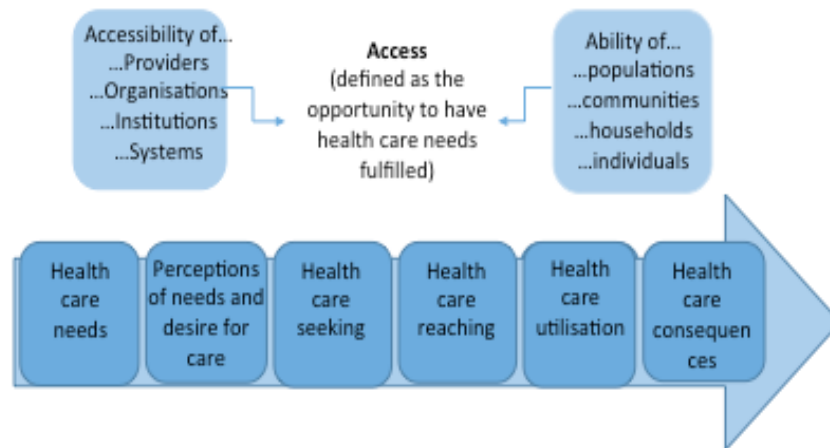


Figure 4: Pathway to care (Levesque et al., 2013)

The socio-psychological perspective considers decision-making at different stages of seeking care but it is limited when it comes to proposing strategies for change (Mackian et al., 2004). Health care seeking theories, such as the social behaviour model and the theory of reasoned action (TRA), focus on the motivational aspects of disease control and the influence of social networks on an individual's behaviour (Hausmann-Muela, Ribera, & Nyamong, 2003). The theories show how demographic and social factors affect attitudes, and perceived risks and benefits of seeking care, which may lead an individual to action. However, these studies do not take into account structural factors which prevent utilisation of care such as limited access, availability of resources, or enhancement of stigma by health professionals. Interventions arising from a mainly socio-psychological perspective focus on patient

education which is often a top down strategy implying that knowledge is the key barrier to seeking care.

2.4.7 Combining the health system, community/cultural and individual perspectives

Social Ecological theory on health describe the interaction between individuals, society, public policy and the health system. This model places the individual within the larger social system and describes the interaction and influence of the multiple levels and how these can affect health outcomes (Golden & Earp, 2012). Health behaviour and health outcomes operate within complex systems that have multiple levels of influence (Gillen et al., 2014). The social and physical environment, political will and an individual's beliefs can all interact to influence behaviour. Reviewing the literature from an array of theoretical perspectives that span different Social Ecological levels of influence can provide a broad insight into health behaviour.

2.5 Research regarding private health care use

2.5.1 Pluralistic Health Care Systems

The position of the private sector in health care needs to be understood in the context of pluralistic health care systems as both private and public sectors interact (Mackintosh et al., 2016). Factors that influence how people interact with the health care system can be categorised as: System factors (structure, regulation and performance of the health care sector), Population characteristics (health seeking behaviour, socioeconomic status and economic capacity), Private and public provider

characteristics (objectives, competence, size) and Performance (quality, equity and efficiency) (Morgan & Ensor, 2016). Private sector use is influenced by the availability and style of private sector providers, the accessibility of public provision and the reliance on out of pocket payments (Mackintosh et al., 2016).

2.5.2 The increasing role of the private sector in low and middle-income countries

As highlighted above, the private and public sector are intrinsically linked and the private sector varies greatly in style and quality. For the last 50 years, most international health research has focused on the public provision of services (Hanson et al., 2008). Governments, international agencies, and researchers have focused on planning and developing these services. It has become clear from indirect evidence, such as household surveys and anecdotal observations, that private health-care provision is growing rapidly (Mills et al., 2002). It is often the dominant provider in some countries, yet there is very little specific data available on what is available in the private sector and its quality of care (Hanson & Berman, 1998; Hanson et al., 2008). A report by the International Finance Corporation a decade ago estimated that over half the health care provision in Africa comes from the private sector and it is expected that this has increased significantly since then (Corporation, 2007). In India, 82% of outpatient care is provided by the private sector (Marriott, 2009). A recent series in the Lancet highlighted the large and expanding role the private sector in health care plays in the health care systems of all low income and middle-income countries (Horton & Clark, 2016).

2.5.3 Understanding Private Health Service Provision

Private providers range from traditional healers and market drug-sellers, to highly qualified, specialist hospital consultants (Horton & Clark, 2016). In some literature, private providers are all those who work outside the public health care system, including non-profit-making community- and faith-based Non-Government Organisations (NGOs) (Malmborg et al., 2011). When developing the literature search criteria, an initial search showed that there are very few articles regarding the private health sector in Sudan and so it was decided to broaden the literature search to examine literature on the private health sector in low and middle-income countries more generally to understand the role that private providers play in health care provision.

The private health sector in sub-Saharan Africa is large and varied. It is estimated that of the \$16.7 billion spent on health expenditure in sub-Saharan Africa, 60% of it was funded by individuals (rather than by insurance schemes), and half of this expenditure went to private providers (Ghatak et al., 2008). The main services offered privately are curative and pharmaceutical. One study of private providers in Kampala, Uganda, found that the quality of providers is varied, some facilities met the Ugandan Ministry of Health standards, but many of the clinics and facilities assessed were found to be poorly equipped and have poor hygiene standards (Lule & Allwright, 2003). There is also concern that some of the services offered in the private sector are of low technical quality, especially for those services accessed by the poor (Patouillard et al., 2007). Two main reasons suggested for the increased

private sector use, despite this low quality, are the restrictions in the national health budget and the pressure from donor agencies as a way of mobilising/redistributing resources. In Zimbabwe, it was estimated that 66% of doctors are employed in the private sector (Bennett et al., 1997), in Malawi, 40% of health care is private (Banda & Simukonda, 1994), and in South Africa, this figure was 58% in 1987 (Price, 1994). However, these studies are all more than seventeen years old, so it is anticipated that the trend has continued and these figures will now be much higher. A review by USAID in 2010 looked at the trends of private sector health care use in 16 countries across sub Saharan Africa, Asia and Latin America (Pomeroy, 2010). It showed a significant increase in private health care use in the previous 13 years across all the countries. It was suggested that the reason for this increased trend was not homogenous across all the countries and ranged from increased economic status, competition and the ability of private facilities to reach those who could not access public services.

One study from Sri Lanka, compared quality of care in public and private outpatient clinics (Rannan-Eliya et al., 2015). It found that while people perceived a higher quality level of care at private centres, there was little difference in the actual quality of care being offered. The public sector was found to be better in the technical aspects of care (diagnosis, examination, investigations) while the private sector was found to be better in patient education due to having increased consultation times and interpersonal satisfaction such as convenient opening hours, easier, more accessible location (near transport links) and pleasant attitude of staff (Mills et al.,

2002). This was consistent with a review of private sector services for tuberculosis (TB) malaria and sexually transmitted infections (STIs) in Asia that found the accuracy of diagnosis and correct prescription was higher in the public sector (Patouillard et al., 2007).

A common assumption made about private providers is that they are predominately used by the higher socioeconomic status groups in a community (Ghatak et al., 2008). However, often customers have very varied economic and social backgrounds (Vogel & Stephens, 1989). A study in Kampala aimed to test this hypothesis in low-income communities (Lule & Allwright, 2003). The researchers used a quantitative survey to identify private and public sector use, and the factors influencing choice. They found that 89% of participants used the private sector and this was not affected by age, occupation, education, income, or religion. Many respondents said that the private provider was cheaper, even when the public health facilities were meant to be free (Lule & Allwright, 2003). Unexpected direct costs in the public sector, such as consultation fees, record card costs, and additional diagnostic tests, can be prohibitive, as can high indirect costs such as long waiting times and higher transport costs (Lule & Allwright, 2003). As highlighted above, it has been identified that women prefer private health providers as private clinics often have increased privacy, patient-friendly opening hours alongside reported improved staff attitudes when compared with the public sector (Malmberg et al., 2006).

In Vietnam, the private sector provided over 60% of all outpatient care in 1997. An analysis from the Government Vietnam Living Standards Survey, found no difference in education, income, sex, or place of residence between public and private health service users (Ha et al., 2002). The Kampala study discussed above, found that while the users of private sector were also very varied, there were very large cost differences between public and private users, with private users facing half the financial burden of those using the public sector. This finding challenges the misconception that the private sector is more expensive and that often the public sector has many hidden charges and costs (Lule & Allwright, 2003).

Other research identified that the main users of the private sector in Africa are not only the wealthy. In Ethiopia, Nigeria, Kenya, and Uganda, 40% of people in the poorest 20% income group use private for-profit providers (Ghatak et al., 2008). Studies in Uganda and other low and middle-income countries, have found that people use the private sector for convenience, availability of services, perceived quality of customer service, and a quick response (Garner & Thaver, 1993; Lule & Allwright, 2003). One entrepreneur in Kenya for example, has set up a business to open private community-based clinics where the typical patients are low-income labourers who cannot afford to lose wages by waiting in long queues in public hospitals (Ghatak et al., 2008).

2.5.4 Role of pharmacies in low and middle-income countries

Pharmacies are the preferred source of health facility for medication in many countries (Kamat & Nichter, 1998), and studies have shown that in many LMICs patients pay out-of-pocket for health care including buying medicines from retail pharmacists instead of accessing medicines in public facilities (Mhamba et al., 2010). Studies in India have reported that 64% of people who buy medicine at a pharmacy have no prescription (Van Sickle, 2006), and this level is higher in other countries (Van Sickle, 2006). In Vietnam, 80% of antibiotics bought for children in the month of the study were done so directly from a private pharmacy without a prescription (Larsson et al., 2000). Pharmacies are often absent from the literature on private sector use and merit further study given the evidence of their important role in health care, especially for the poor (Hanson & Berman, 1998). Self-diagnosis and self-medication is correlated to income level with the poorer quintiles selecting pharmacies more often as it is viewed as a more affordable way of obtaining care (Awad et al., 2006). However, self-medication can be problematic and is potentially associated with many problems including incorrect self-diagnosis and the inadequate treatment of a disease that could result in disease progression and increased complications (Awad et al., 2006). Inappropriate dosing may result in serious morbidity and mortality, poor patient outcomes and adverse drug reactions (Awad et al., 2006). The pharmaceutical industry is unregulated in many countries and there are few legislated price controls which can result in a wide variation of prices and of services offered by the pharmacist beyond drug dispensing, such as counselling and patient education (Mhamba et al., 2010).

2.5.6 The link between understanding private sector use and non-communicable disease

The availability of medicines for acute and chronic conditions in LMICs is a key issue in both the private and public sectors and the shortages are more severe for chronic conditions (Cameron et al., 2011). One study compared the different availability of drugs to treat chronic conditions in the public and private sectors across 40 countries (Cameron et al., 2011). It identified that the difference in availability was greater for anti-asthmatics, antidepressants and anti-epileptics, with far fewer of these drugs (both generic and branded) available in the public sector. The authors suggest that demand for these drugs far outweigh supply in the public sector and are a contributing factor to choosing private health care. Other studies concur that poor performance and lack of available drugs in the public sector lead to increased private sector use; for example, in Tanzania, evidence suggests that the percentage of people using the private sector increases when public sector health care providers run out of drugs (Morgan et al., 2016).

2.6 Research applying theories and models of asthma care seeking and asthma service utilisation for patients in low and middle-income countries.

2.6.1 Asthma care within the private sector: the health system perspective

There is little published literature on the provision of asthma in the private sector from any country. This is because private health care is often unregulated and national statistics on use are not as routinely collected as they would be in the public sector. Rarely is private sector use analysed on a disease by disease basis. Therefore it is hard to know the level of private sector use for asthma care but it is suggested that where availability of asthma diagnosis and treatment in the public sector is very low, private sector use is likely to be very much increased (Lessing et al., 2013). One study in Nigeria found 29% of public facilities surveyed had a spirometer and 38% had a peak flow meter, it is not known how this compares to the private sector in the country (Desalu et al., 2011).

A cross-sectional study of pricing and availability of asthma drugs in 52 LMICs, focused on the three drugs listed as essential medicines by the World Health Organisation: beclomethasone, salbutamol, and budesonide (Lessing et al., 2013). Beclomethasone was only found to be available in the public sector in nine countries surveyed (Afghanistan, Egypt, Honduras, Mali, Nepal, Sri Lanka, Uganda, Vanuatu, and Zambia). Budesonide was available in eight countries (Chile, India, Nepal, Peru, Philippines, Thailand, and Tuvalu). Only one country, Nepal, was found to have all three drugs available in the public system. The study found a higher level of availability in the private sector; 23 countries had beclomethasone and 26 countries

had budesonide. 14 countries had no access to any of the three drugs in public or private facilities. Affordability of these drugs was also considered in the study, and for a single beclomethasone inhaler the relative cost ranged from half a day's wages in Afghanistan to 14 days wages in Madagascar. For budesonide, where available, the range of relative cost was even larger; half a day's wages in Jordan to 107 days wages in the Republic of Guinea (Lessing et al., 2013).

One study in Chennai, India, used mystery clients to look at asthma management and advice given at private pharmacies (Van Sickle, 2006). It found that, of the 52 pharmacies visited, none recommended the WHO-preferred inhaled medications. It also found that the majority of medications issued had some information on dosage, expiry date, or ingredients missing. Frequently, the antibiotics that were obtained were requested as a result of self-diagnosis and suggested that asthma had not been diagnosed but had been mistaken as a respiratory tract infection. This study was only conducted in one city in India so its generalisability could be questioned, however, other studies have shown high levels of private pharmacy use in unregulated settings (Larsson et al., 2000), and therefore this situation is expected to be similar elsewhere. A mystery client survey of pharmacists in Khartoum and Gezira, Sudan found similar results to the Chennai study (Osman et al., 2012). Of the 105 pharmacists approached, only 3.8% demonstrated adequate inhaler technique advice, and only one (0.9%) was judged to have an optimal technique. The remainder of pharmacists did not demonstrate that they knew how to use the inhaler properly.

Many pharmacists felt that this was not part of their role and that doctors should advise on inhaler use.

It is suggested that limited access to health care increases the need for pharmacists to take an active role in asthma care as they are often the first and repeated point of care (Osman et al., 2012). A case control study in Khartoum, found that an intensive training package for pharmacists could lead to a positive impact for patients, leading them to take a more active role in their asthma management and gaining a greater awareness of their disease and its treatment (Abdelhamid et al., 2008). The vital role that pharmacists play in asthma care in Khartoum and the potential for their role to be developed and strengthened was a key stimulus to include them in the health facility survey component of this study.

2.6.2 The vital role of the private health sector in Sudan

Sudan has a large and growing private health sector which absorbs 66.9% of the total health expenditure (Etilib et al., 2010), although some literature suggests that this figure is nearer 79.3% (SCF, 2005). The private sector is concentrated in urban areas, particularly in Khartoum and Gezira states. Of the 229 private hospitals and medical centres registered with the Federal Ministry of Health, 70% are in Khartoum. These providers are diverse and range from traditional healers and minimally trained drug-sellers to qualified doctors and specialists (Malmborg et al., 2006). As mentioned above, low public confidence in the public health care system leads to a booming private sector (Lessing et al., 2013).

2.6.3 Self-management of health conditions

In Sudan, 70% of people who did not seek health care when sick stated that lack of money was the main reason for not accessing services (SCF, 2005). It was found that people with lower incomes were more likely to self-medicate than those who were more affluent, as they cannot afford to routinely consult medical practitioners (Awad et al., 2005). One study in Khartoum, found that 81% of the 1,000 study participants used medicines (including herbs), in the two months prior to the study, without a medical consultation (Awad et al., 2006). Many medicines can be obtained from pharmacies without a doctor's prescription (Awad et al., 2006). This can lead to incorrect self-diagnosis, inadequate treatment of a disease, or incomplete treatment courses. The main source of these self-medications were private sector pharmacies (Awad et al., 2005). Self-medication was found to be most associated with middle-aged women (between 40 and 59 years) with low monthly income. The main motivation for self-medication was that it was considered as a low-cost alternative to health-care facilities which charged consultation and laboratory fees (Awad et al., 2006).

2.6.4 Perceptions and beliefs of asthma patients: the individual perspective

There has been limited research examining how patients perceive their asthma conditions, and the beliefs that they associate with the disease. One study in India used a quantitative survey to collect information on the knowledge, attitudes, and practices of asthmatic patients (Prasad et al., 2003). It found that while most people

did not know the cause of asthma (79%), others thought it was hereditary or due to an allergy (11% and 9.6%, respectively). 50% of patients believed asthma was infectious, 12.6% thought it was the curse of God, and 12% thought it was due to smoking/addiction. None of the patients knew about peak flow meters and lung function tests as a means to monitor their disease. One third of patients that were prescribed inhalers stopped using them because they thought they were habit-forming (53%), expensive (66%), or difficult to use (63%). All the patients surveyed had taken allopathic treatment. Several other studies have also highlighted the use of herbs for controlling asthmatic symptoms in Sudan (Awad et al., 2006; Merghani et al., 2012). It was found that 44% of patients included in the study had tried non-medical treatment for the disease, such as honey, kammon³, cigarettes, praying and reading the Quran (Merghani et al., 2012). The impact that living with a long-term potentially life threatening disease such as asthma has on patients is not often reported and yet can be extremely significant; 88% of patients surveyed believed that they could not live a normal life, and 74% believed that their condition was potentially fatal (Prasad et al., 2003). It was suggested that a major problem with asthma management was the distorted information given to patients, and the knowledge patients have regarding their disease (Enarson & Ait - Khaled, 1999). Many asthma interventions have focused on treatment regimens or education

3. Kammon is also known as Nigella seed or black cumin

regarding inhaler use but not on how to advise patients to cope with the psychological effects that living with asthma can bring. Access to quality health information which explains the symptoms, treatment options and where and which services are available is viewed as crucial to provider choice and adherence to treatment (Morgan et al., 2016). One study in Nigeria found that asthma information posters and leaflets were found in only 53% of facilities surveyed (Desalu et al., 2011).

2.6.5 Perceptions and beliefs of asthma patients in Khartoum state

One survey conducted at the three main public teaching hospitals in Khartoum, found similar results to those identified by Prasad et al in the Indian study described above (Merghani et al., 2012). 67% of patients believed asthma was inherited. However, in contrast to the Indian study, only 5% of patients believed asthma was infectious. 27% of patients refused to be diagnosed as asthmatic and only accepted the diagnosis of allergy. 46% of patients did not use preventers (inhalers or tablets), but of those who did use inhalers, 88% had no objection to them. Poor adherence to asthma treatment and on-going management is associated with worsening of symptoms (ibid).

2.7 Understanding choice of provider for asthma care

Most of the studies outlined above have looked at health-seeking behaviour and choice of provider in general, rather than on a disease-specific basis. There is very

little literature that breaks down choice of provider per disease or health condition. Therefore, it is not known whether patients make very different decisions on choice of provider based on the severity or chronic nature of their condition. Choice of provider regarding long-term NCDs may be very different from managing an acute episode of a communicable disease such as fever or diarrhoea. People who are ill must decide whether or not to seek care, as explored in the literature on Health-Seeking Theory (in section 2.4). Once decided, they must select their preferred type of care, including self-treatment, different providers, and public/private or traditional/western medicine (Lavy et al., 1994). Asthma is a disease that combines acute attacks with a need for long-term management, and therefore it is anticipated that choice of provider and decision-making is not straightforward. This, coupled with the severe shortages of medicines in many countries (Lessing et al., 2013), highlight the importance of understanding how the different push and pull factors interrelate. Understanding why people with asthma choose one type of care over another can give policy makers insight into where and how to improve services.

2.8 Methodological approaches used in health care utilisation models

The methodologies described in the literature regarding health care utilisation and health care seeking can be categorised by research techniques depending on whether the focus is the health care system end point (access and barriers) or whether it is describing the process of seeking care. Health care system analysis has primarily been conducted quantitatively by either health facility surveys or by household surveys. These give the ability to gather information from large numbers

of people or facilities. There are limitations though, how a household survey is conducted can affect results, as the participant can often perceive the questions are referring only to the formal health care system. An example of this is that visiting traditional healers is commonly reported in qualitative studies, but very low levels are found in quantitative household surveys (from 0.5% in Ethiopia to 4.6% in the Democratic Republic of the Congo) (SCF, 2005).

A few studies use a mixed methods approach in which qualitative in-depth interviews are conducted initially to gain an understanding of care utilisation, and then a quantitative survey is conducted to look at frequency of facility use on a larger scale (Habtom & Ruys, 2007; Moran et al., 2007) but there have been no mixed method studies on asthma care or asthma service provision. As outlined in Chapter 3, a mixed method approach was chosen for this study as being the most likely to include the broadest range of information from health facility provision to individuals' attitudes and beliefs.

2.9 Methodological approaches used in pathway to care theory

Studies of the process or pathway to care, health-seeking behaviour, perceptions of illness, and causal attributions are often investigated using qualitative methods. These investigations often use an ethnographic approach to elicit illness narratives (Patel et al., 2008; Shaikh et al., 2008) to look at care-seeking in relation to illness and delivery. Other studies have used semi-structured interviews to investigate perceived disease causation (Weiss et al., 2008) and treatment pathways (ten

Asbroek et al., 2008). These techniques aim to gain an understanding of the perceptions and impact of values and beliefs on provider and facility choice (Grundy & Annear, 2010). Pathways to care are also investigated via household surveys, using structured interviews. These surveys focus on the pathway to care and answer questions about facility use and household characteristics, but may not answer the reasons as to why these decisions are made (Grosh & Glewwe, 2000; Sharma, 2008).

2.91 Conclusion

The review of relevant theoretical frameworks, extant academic literature and practitioner data has identified the patient choice of care provider as a complex decision-making process. That decision is influenced by many factors from both the health care system supply-side and from the individual patient's beliefs and cultural practises. Pathway theories describe the series of steps an individual takes and highlight the factors that influence that journey from a health system perspective (Mackian et al., 2004).

This research employs a Social Ecological approach that examines the multiple levels of influence affecting health outcomes from the individual, the interpersonal, societal, the organisational and public policy. These levels interact to influence access to asthma care and the types of care sought which gives an insight to understanding the choice of provider. Historically, the three approaches (system approach, Socio-Cultural approach and individual approach) were often presented separately and therefore it could have appeared that the health care seeking factors

influencing access were unconnected to the individual's decision-making process or to the influences of the wider community.

Health service research has been criticised for being too narrow and descriptive; that what is needed is to show how these theoretical approaches interlink to improve service delivery and use (MacKian, 2003). Therefore, this research will adopt the Social Ecological approach which views individuals as embedded within larger social systems and that individuals and their environments continually interact and affect health outcomes (Golden & Earp, 2012). Figure 5 below sets out the multiple levels of influence and aims to demonstrate these levels are interactive and reinforcing. The figure sets out the different influences involved in asthma care seeking and choice of provider by the patient. This holistic approach can then lead to identifying potential areas in asthma service delivery that could be strengthened. As the literature review highlighted, little is known about if, how, why and when patients seek care for asthma. The theoretical models on the health system factors to service provision were combined with the theories surrounding an individual patient's pathway to utilising care and were used to help design the research.

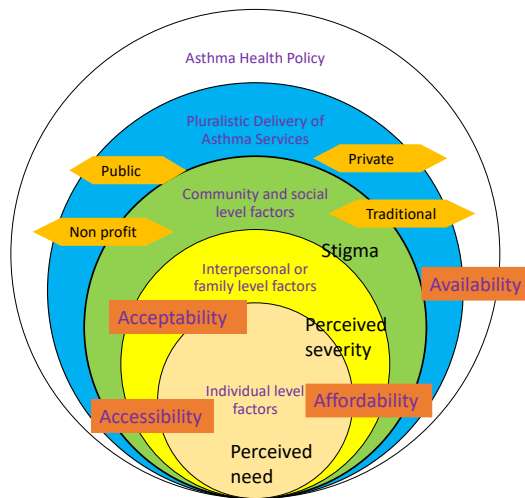


Figure 5: Conceptual framework: multiple levels of influence affecting asthma services in the private sector

The literature outlined above enabled a picture to be built of the potential factors that influence health seeking and health care utilisation. The research focus was on gaining an understanding of the predisposing variables of care-seeking (risk factors and health-related attitudes), the enabling variables (availability of treatment, affordability and acceptability of services), social factors and the perceived outcomes and consequences of seeking care. Prior experience of the real situation in Sudan suggests that health system factors regarding the provision and availability of services and patients' pathway to care are intrinsically linked and that decisions regarding care-seeking involve a multitude of interlinked factors that combine the individual with the health care system.

Chapter 3: Research methodology

3.1 Chapter summary

This chapter outlines the research approach and methodology identified from the literature, to best fit the research questions set out in the Analytical Framework in figure 6 (page 77). It also outlines the rationale for choice of the Analytical Framework (Figure 6), the data collection process, and the data analysis method. Currently very little is known about private asthma service use in Khartoum. As a result, I adopted a pragmatic Social Ecological approach to examine a wider perspective by drawing on both quantitative and qualitative research methods. The research design was constructed as an explanatory sequential mixed methods study (Creswell, 2013). The quantitative research (a health facility survey) was conducted first, in order to identify the asthma services available in private facilities (the organizational/ health care system level of influence). This was followed by qualitative research with asthma patients to explore their decision-making around asthma health seeking and asthma facility choice in more detail (the individual health seeker level/ intrapersonal and interpersonal/ family level) and the societal level factors that influence decision-making.

3.2 Overall design

The literature highlighted that there is a need to develop a tool for understanding how people engage with health care systems holistically, rather than either describing the process of seeking care or describing the health care system endpoints. This informed the overall design of the research methodology by

developing a two-phase approach that would combine an identification of systemic factors driving private health care choice and mapping of the process involved in health seeking. The quantitative health facility survey collected information on asthma services available from a large number of private facilities (breadth). The qualitative in-depth interviews explored in more detail the process and rationale of health decision-making of adult asthma patients (depth), with a focus on their individual decision-making regarding public or private care and their complicated health care seeking process.

“Any research interest in health-care seeking behaviour, focusing on end point utilisation, needs to address the complex nature of the process involved, cognisant of the fact that the particular ‘end point’ uncovered may be multi-faceted and not correspond to the preferred end points of service providers” (MacKian, 2003)(Page2).

The private sector provision of asthma treatment in Khartoum was investigated from both the health care system perspective (phase 1: availability of resources and facilities) and the individual’s perspective and decision-making pathway (phase 2: health-care seeking behaviour and patient choice).

The Liverpool School of Tropical Medicine provided financial support for the data collection in Sudan – this included funds for my travel to and from the country, for the employment of the data collection team and the translations.

3.3 Rationale for design choice

The literature review of private choice of provider in low and middle-income

countries and the health-care-seeking behaviour of asthma patients, led to the adoption of the conceptual framework (figure 5). The literature outlined that there are many factors that interact and influence the choice of provider, including contextual factors, health care system factors, and patients' beliefs and cultural norms. A person's decision to attend a particular health facility is based on a combination of need, social forces, and access issues such as accessibility, availability, acceptability, and affordability (Hausmann-Muela, Ribera, & Nyamongo, 2003).

A number of authors recommend a combination of research methods, using qualitative methods to inform survey design or utilising survey respondents or findings to provide more in-depth information (Creswell, 2013; Russell, 2005). It is this latter design that was adopted for this study as so little was known about which asthma services were available in the private sector in Khartoum, it was felt that it would be best to get a broad quantitative overview of what was available and where. With this acting as a description of the health care system environment, the in-depth interviews could provide more detail as to if, why and how the services are accessed. Therefore, a quantitative health facility survey was developed to investigate the health care system factors from a health system perspective while qualitative in-depth interviews investigated asthma provision from the patients' perspective.

The relationship between the research questions, objectives, and research area of this thesis is depicted in Figure 6. It describes the areas for analysis from a health

care system approach (barriers and facilitators) and the individual's decision-making pathway incorporating familial and societal influences. Through combining these theoretical determinant perspectives, the research is able to provide a novel and more holistic perspective on accessing asthma services in Khartoum.

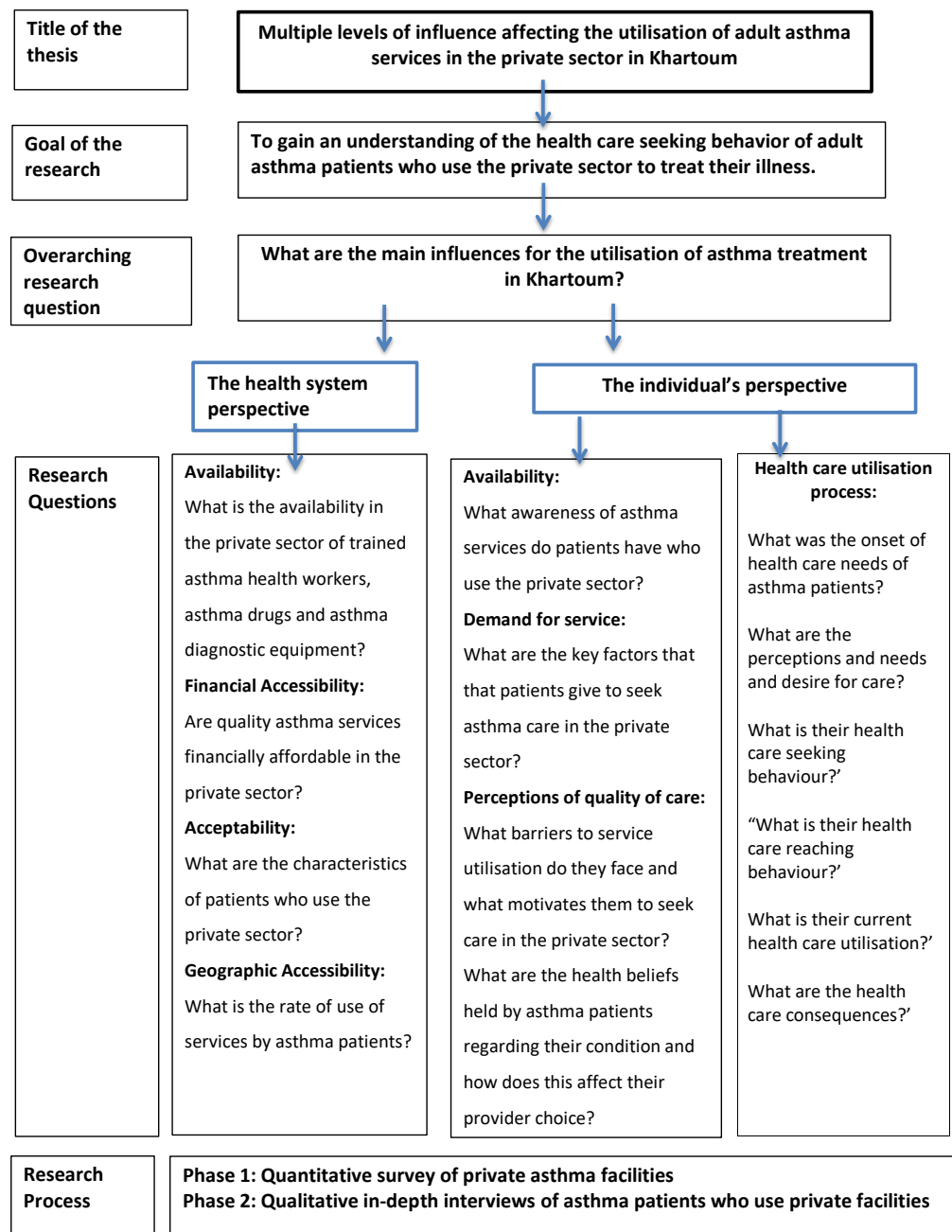


Figure 6: The Analytical Framework

The study area:

The Republic of Sudan (Sudan) had a population of 32,671,000 in 2011, after the secession of South Sudan (WHO, 2011). Life expectancy at birth is 59.8 years which is below the average of 70 years for north Africa (WorldBank, 2010) . Khartoum is the capital and most populated state in Sudan. It has an area of 22,122 km² and an estimated population of 7,152,102 (Sudan, 2009).

Prior to secession in July 2011, Sudan was the largest country in Africa. With an area of 1,886,068 km² (728,215 square miles) it is now the third largest country on the continent. It has land borders with Egypt, Eritrea, Ethiopia, South Sudan, the Central African Republic, Chad, and Libya. 84% of the population live in urban areas (Awad et al., 2006). Sudan is a country that has been troubled by civil unrest; since 1983 it is estimated that a combination of civil war and famine has taken the lives of nearly 2 million people (BBCWorld, 1998). The country is undergoing rapid urbanisation which is placing pressure on basic services such as health and education (Pantuliano et al., 2011).



Khartoum is the capital city of Sudan and has an overall population of 7 million people. The population of the city has doubled in size since 1990. Approximately 60% of the population are poor (Pantuliano et al., 2011).

The city consists of three urban areas: Khartoum, Khartoum North, and Omdurman, which are divided by the Nile and its two arms. Khartoum's urban area is the largest of the three urban areas, is the oldest part of the city, and houses the government offices and commercial sector. All three urban areas have undergone rapid urbanisation and have seen a large influx of internally displaced people from other areas of the country.

3.4 Phase 1: Understanding from a health system perspective: A health facility survey of private hospitals, private clinics and private pharmacies

Objective 1: To examine the provision of asthma diagnostic and treatment services available for adult patients in the private health sector, in Khartoum.

3.4.1 Stage 1: Mapping of health facilities

Stage 1: A mapping exercise was conducted to identify the number of registered private hospitals, clinics and pharmacies that offered asthma services in Khartoum.

The Ministry of Health (MoH) provided a list of all the private facilities in Khartoum city that were listed as registered in 2014 (year of the data collection) and which facilities offered asthma services. Of the registered private health facilities that provided asthma services in 2014, there were 21 private hospitals, 9 private chest clinics, and 444 private pharmacies. In Khartoum, there are more private facilities that were not registered with the Ministry of Health (MoH) but unregistered facilities are often harder to find as they may be unlicensed and may not be in existence long-term. Therefore, it was decided these facilities would not be included in this survey, as they could potentially provide quite different findings to the registered clinics. It is also hoped that the results of this survey could be replicated in the future to monitor any changes and using an official list of facilities will make it easier to return.

All the private hospitals and private chest clinics offering asthma services registered with the MoH were invited to participate and be surveyed. After several attempts

and repeated visits (to ensure suitable time of day and availability of a health worker) all the clinics and hospitals agreed to be part of the study.

Pharmacy providers were stratified according to location and randomised (Hayes & Moulton, 2009). Annex A gives a list of the facilities surveyed. The sample size for the survey was determined with a 90% confidence interval rate (CI), and a precision estimate of +/- 15%. There are 444 registered pharmacies split across three sub-districts of Khartoum (302 in Khartoum sub-district, 78 in Alshodha, and 64 in Khartoum East). Each of the three sub-districts were randomised separately using Excel to account for the difference in number of facilities. A random sample of 10% from each sub-district was chosen for the survey. The mapping and selection of facilities took place between January 2014 and April 2014.

Table 6: Type of facility surveyed

Type of health facility	Number surveyed (% of registered facilities)
Private Hospitals	21 (100%)
Private Chest clinics	9 (100%)
Private Pharmacies	44 (10%)
Total	74

3.5 Stage 2: Quantitative Data collection

A facility-based cross-sectional survey of private providers in Khartoum (both health care and drug providers), was conducted to collect information on their current asthma treatment provision. A structured questionnaire was developed based on WHO Health Facility Survey Guidelines (WHO, 2003) and the Global Initiative for Asthma (GINA) Guidelines (Beasley, 2011), and was pre-tested. The questionnaire was conducted in English between June and September 2014, the questions and answers were stored on smartphones. In order to answer the questions on access, the main focus of the questionnaire was on availability and accessibility. The WHO health facility questionnaire was adapted to contain the following seven sections that were used in a recent study in Nigeria (Desalu et al., 2011).

1. Profile and type of the provider
2. Asthma services offered and availability of basic infrastructure: asthma clinics, asthma registers, asthma protocol, evidence of asthma care training
3. Number of asthma patients (one off and repeat)
4. Patient profile
5. Availability of functional facilities like pulmonary function test equipment (spirometer and peak flow meter)
6. Availability, type and price of essential asthma drugs
7. Facilities for health asthma education and support

The questionnaires (Annex C) consisted of two types of question. The first type were closed-verifiable questions, such as 'do you have a peak flow meter?' In the second

type of question, health workers were asked to give their opinion based on their experience working with asthma patients such as ‘why do some patients stop asthma treatment?’. The answers for these were recorded verbatim for short answers (one sentence or less) while longer answers were summarised by the research team. A weakness of the electronic questionnaires was that long answers were difficult to capture effectively on a smartphone as they involved in-putting the text using the touchscreen keyboard.

The private health providers were visited on an individual basis at their health facility (private hospital, clinic or pharmacy). At each health facility, the Senior Manager was met and asked for permission to conduct the research. They were then asked for the names of the health workers who fulfilled the inclusion criteria. One health care worker at each participating health facility and pharmacy was surveyed.

3.5.1 Inclusion criteria for the survey:

- The provider provides care to adult asthma patients
- They consent to be surveyed
- They have regular contact with asthma patients
- They provide an asthma diagnostic or treatment service for a fee.

A research team of three experienced researchers (two women, one man) then went to where the health worker was working within the health facility. The rationale for using a research team rather than collecting the data myself is discussed below in section 3.5.4. For pharmacies and clinics, this meant in the main building

and waiting until the individual was free from seeing patients. In the hospital, this was more complicated as the health worker could be in the outpatient department, emergency room or conducting other hospital duties. Asking the Manager to nominate persons to survey was open to bias (as they may have only suggested people who would give a favourable opinion of the facility) but it was the most effective way to select people as there was no central place the health workers congregated or up to date personnel lists.

The research team used mobile handheld smartphones which stored the questionnaires and inputted the responses given by the health worker. The use of electronic questionnaires has been shown to improve time and accuracy when compared to paper questionnaires (Ahmed et al., 2018). The research team asked the health workers the questions and then recorded their answers in the electronic questionnaires. The answers were exported to Excel, which I analysed using descriptive statistics.

During the data collection period (January 2014 – December 2014), I visited Khartoum and worked with the data collection team four times each for a period of two weeks. I kept in regular contact with them when I returned to the UK and had weekly skypes to discuss the progress of the work.

3.5.2 Piloting of the survey

The questionnaire was tested through a pilot sample encompassing each of the facility types in the nearby city of Omdurman. Omdurman was identified as the best

fit for the pilot because it is the next geographic city to Khartoum, and shares many of its characteristics. It has a high number of private facilities, a weak public health service, and it is a densely populated urban area.

To ensure the efficacy of the questionnaire across a range of settings, the following facilities were piloted, I selected different types of private facility.

- For hospitals: one large, specialist, high-tech hospital and one smaller, general hospital
- For clinics: one specialist clinic of a chest physician and one general practice small clinic
- For pharmacies: one that was part of a large chain of stores and one independent pharmacy.

As a result of the six electronic questionnaires conducted in the pilot, areas for improvement were identified including the need to make the survey specific to the level of facility (i.e. one survey for the hospitals, one for the clinics, and one for the pharmacies). Initially, I had planned to mark the facilities using global positioning systems (GPS) and Google Earth, and photographically capture each location. It was hoped that these maps would show the proximity of health facilities to each other and whether they were located in residential or commercial areas. However, it quickly became apparent that it is illegal to take photos of hospitals in Sudan, and that Google Earth is banned in the country. Therefore, the name of the facility and its location were recorded instead.

A key aspect of access is affordability; however, it became clear during the pilot that health providers were not in a position to answer financial questions, as these were handled by a different part of the hospital or clinic and by different staff. Therefore, for pragmatic reasons, the research design was adapted to explore perceptions of cost solely within the qualitative phase.

3.5.3 Quantitative data collection

In Khartoum, there are 21 registered private hospitals that offer asthma services, 9 private chest clinics and 444 private pharmacies. The health facility survey was conducted at all 21 private hospitals and all 9 private chest clinics. The pharmacies were randomly sampled and 44 pharmacies were selected and surveyed.

The main focus of the health facility survey was to obtain information on the types of asthma services available and then to ask health providers to provide their opinions on why and how asthma patients seek care.

The survey focused on the following categories:

- **Availability:** levels of trained asthma health workers, asthma drugs, registers, guidelines and asthma diagnostic equipment
- **Accessibility:** Understand the rate and type of use of services by asthma patients
- **Acceptability:** Provider perspectives of the health- seeking behaviour of patients who use the private sector

Table 7 shows the number of health providers that took part in the survey, the type of institution in which they worked, and their current job title.

Table 7: Profile and type of provider surveyed

Type of health facility	Survey Respondents	Job Specialism
Private Hospitals N=21	19 Doctors (11 women, 8 men) 2 Nurses (1 male, 1 female)	General hospital doctors General hospital nurses
Private Chest clinics N=9	9 Doctors (3 women, 6 men)	Chest physicians
Private Pharmacies N=44	44 Pharmacists (31 women, 13 men)	Pharmacists
Total	74	

3.5.4 Data management

Prior experience of working in Sudan meant that I felt it would be better to have a Sudanese research team asking the questions as they make the respondent feel more at ease and less like they needed to present a 'perfect picture' in their responses and therefore it was decided to recruit a local data collection team. As I only speak English, the questionnaires were designed by me in English. They were

then converted into electronic format using Open Data Kit (ODK)⁴ software for use on mobile phones. ODK does have a translate function which theoretically could automatically translate to make it easier for the survey team. However, as Arabic varies from country to country, the automatic translation was not of high quality and therefore the Sudanese team could not understand it properly. The data collection team were an experienced team of three researchers (two women and one man) and they were trained by me on conducting the questionnaire and using the handheld devices. For training purpose, the questionnaires were printed and translated into Arabic by professional translators and then translated back in order to check accuracy. This mean that the questions could be fully explored and understood in both English and Arabic by the data collection team during the training. The data collection team practised completing the questionnaires and how to ask the questions in English. They also assisted by identifying concerns when they felt a question might be confusing or too vague.

The survey of asthma service providers collected information on the current asthma treatment provision at their facility. These health providers gave information on the type of facility (hospital, chest clinic, pharmacy), their professional status (doctor, nurse, pharmacist), level of asthma treatment provision available at their facility, estimated numbers of asthma events seen at their facility in one year (one off and

4 Open Data Kit: <https://opendatakit.org>

repeat), asthma drugs stocked by their facility, key diagnostic tools used, and key networks. They were also asked their opinion on how patients utilise asthma services, what their knowledge of the condition was, and why some patients do not comply with treatment. All the health providers treated asthma patients and so were able to answer the questions based on their experience.

A copy of the questionnaires used is included in Annex B. The questionnaires were conducted in English by the Data collection team but if a respondent needed a translation of any terms, the team could use Arabic as and when in order to help the respondent understand what was being asked. Most of the health professionals surveyed had a good knowledge of English, this increased with their level of medical training. Informed consent was collected on paper copies. Another research design adaptation based on the pilot was that while it is possible to use ODK to sign consent, the respondents preferred to sign a paper document that they could read and that they could retain the printed information sheet.

The responses to the questionnaire were entered by the Data Collection team onto the smartphone and, where possible, were instantly sent to the research centre. If there was no Internet reception (3G), then when the phones were returned to the research centre at the end of the day, downloaded onto the central computer and backed up on a separate hard drive for data security reasons.

The ODK results were stored in a protected cloud database that meant they could be accessed (password protected) by the team in Sudan and by myself in the UK. The

benefit of using a software such as ODK was that even when I returned to the UK while the team were continuing with the survey, I was able to continually track the data collection progress and see each day the results from the surveys and monitor progress.

3.5.5 Quantitative Data Analysis

The survey findings were downloaded from ODK onto three excel sheets (one per facility type (hospital, clinic, pharmacy)). Each row of the spreadsheet represented a facility and each column a survey question. Once the quality of the spreadsheets was reviewed (for gaps, duplication, input errors), then the results in the columns were analysed using descriptive statistics (means, standard deviations and percentages where appropriate).

3.6 Phase 2: Understanding from the individual's perspective

3.6.1 In-depth interviews with asthma patients

Objective 2: To identify the factors that result in asthma patients choosing private health care providers for their treatment.

Objective 3: Explore how and why asthma patients make health care provider choices within the private sector

The second phase of the research was based on models of health-care-seeking qualitative research (Good, 1987) (Lavy et al., 1994) and built on the findings of the phase 1 provider survey. Exploratory qualitative research with asthma patients who seek care in the private sector in Khartoum was conducted using in-depth interviews between September 2014 and December 2014.

In-depth interviews were chosen as the methodology because they allowed the respondents' feelings and perspectives regarding asthma care to be explored in more detail. Interviews when compared to questionnaires are more powerful in eliciting narrative data that allows researchers to investigate people's views in greater depth (Creswell, 2013). It was felt that other qualitative techniques such as focus groups would be less acceptable as the respondents were being asked about their own personal health status and their care seeking journey which are confidential. According to Kvale, an interview is "*a conversation, whose purpose is to gather descriptions of the [life-world] of the interviewee*" with respect to interpretation of the meanings of the 'described phenomena' (Kvale, 1996)(page 6).

While there is the potential that the interviewer could bias the discussion by asking leading questions, it was felt that the training and piloting of the team as well as the reviews of each transcript and feeding back comments would help to minimise this. A key decision regarding the language that the interview was conducted in was discussed by the broad research team and the different possible models were tested in the pilot stage (as described in the next section).

The interviews were semi-structured and were based on the Peters and Garg model of access (Peters et al., 2008). The interviews were designed to facilitate and progress discussion. They started with an introduction and description by the individual of their background. They were then guided through their experiences of having asthma, their health seeking behaviour and their use of the private sector. They were then asked for their opinions about current asthma service delivery and their motivations for seeking care in the private sector. Finally, they were asked about their suggestions for how and if asthma service delivery could be improved. The topic guide is given in Annex D and was based on the conceptual framework presented in figure 5 which includes discussion on the four components of access of the Peters and Garg model, figure 3 (geographic accessibility, financial accessibility, availability and acceptability) with discussion on the steps along the Levesque pathway to care model as depicted in the Figure 4 (Levesque et al., 2013; Peters et al., 2008).

3.6.2 Piloting the topic guide, role of researcher, and interview style

The piloting of the qualitative phase of the research had two aims. Firstly, it was piloted to test the suitability of the topic guide and to revise the interview tool. Secondly, the pilot provided an opportunity to review the way that the interviews would be conducted, and to test the translation technique that would be used.

The pilot interviews were conducted with two people from Omdurman who suffer from asthma and who have used the private sector for their asthma treatment (Respondents A and B).

One interview (Respondent A) was conducted by me in English, recorded, and then transcribed. The quality of the interview was good, but it was clear that not many patients would be able to discuss their condition easily in English. The next technique that was attempted was line-by-line translation by a translator from English to Arabic, with Respondent B. However, this meant the interview was very stilted, and the participant only gave very short answers rather than giving a fuller narrative of their health-seeking behaviour. I also felt that my presence as a UK national meant that the interview was altered. It appeared that the participant believed that they needed to think more about their answers, in searching for the 'correct' response.

The research design was then adapted based on the finding of the pilot and I worked with three experienced Sudanese qualitative researchers (two women and one man). These researchers had also conducted the quantitative part of the study. I trained them on the topic guide and interview tool. The language was discussed and explored so that it was well understood. Respondent B was then interviewed again in Arabic, which I observed. The interviews were face to face and recorded. By interviewing in the interviewee's own language, it meant that the interview data was captured in its natural form and enable a good rapport to be built with the participant (Ritchie et al., 2013). It provided a much more natural and conversational

discussion (Ruben and Ruben 1995). The participant felt more relaxed and able to give a fuller account of her experience. The interview was digitally recorded, transcribed, and then translated back into English by a professional translator. This latter technique was the most successful which is consistent with the literature on the impact of translations in qualitative research (Temple & Young, 2004) (Santos et al., 2014).

One key aspect that emerged from the pilot interviews was around the definition of asthma. In Sudan, the English word 'asthma' can be used, as it is the direct translation into Arabic which is 'Rabo' (ربو). However, both interviewees and key individuals with whom I discussed the research, said that the most common word for asthma in Arabic is 'hassaseer' (الحساسية). The actual translation of 'hassaseer' is allergy. This term has quite different implications, and therefore became a key aspect to explore in the interviews.

The interviews were transcribed by the research team in Arabic. These transcriptions were then translated by professional translators and then a sample were back translated to check for translation quality.

3.7 Identification of participants and Data collection in Qualitative component

The initial plan was to identify participants for interview through a poster advertising the study and asking people to get in contact. A poster was produced (that was

translated into Arabic by the research team) and advertised the study. This was distributed to the health facilities and in the community setting (such as patient groups and community organisations). This poster contained a phone number for the research team so that the individual could contact the research team directly.

However, there was no response to the poster and so a different method of finding participants was required. Contacting patients while they were receiving treatment at the health facilities was felt to be too direct (and hard for people to refuse) and there are no functioning asthma patient organisations or patient groups that could be contacted so it was felt that using health providers as gatekeepers to provide contacts was a possible option. The providers included in the Phase 1 quantitative survey assisted with identifying patients who attend their centre for the Phase 2 qualitative interviews. They were also informed that the interviews would be anonymised so that it would not be possible to tell which patients were talking about which health facility. The providers were briefed on the inclusion criteria and were asked to try and select a cross-section of patients according to age and sex.

The inclusion criteria for the in-depth interviews was as follows: They were aged 18 years and above, have an asthma diagnosis, live in Khartoum state, had sought asthma care at a private facility (hospital, clinic or pharmacy) and consented to be interviewed. It was aimed to try and interview a balance of ages and an equal mix of male/ females. The purposive sampling frame set out that four patients would be selected from each of the three provider categories (hospital, clinic, pharmacy) with an even split of males and females.

However, this method of selection had the potential to lead to bias (such as people who are expected to give positive responses being selected by the gatekeepers), but this was felt to be the most feasible and convenient sampling method. It also was not possible to find people who had only used one type of provider or who could give their answers in the relation to one provider type so I decided to adapt the sampling frame to become an even split of males and females who had used at least one form of private health provider for asthma care.

In order to avoid coercion, information about the study was given out by providers but patients contacted the researcher not the provider to express interest in the study, to ask questions about it and consider participation. They signed a consent form to demonstrate they were happy to participate. The patients chose whether they would prefer to be interviewed in their home, at the Research Centre or at the health facility. The interviews were recorded using dictaphones and then transcribed in Arabic by the data collection team. These transcriptions were translated into English and checked back into Arabic for consistency and accuracy of translation.

During the health facility surveys, 14 asthma patients were identified and agreed that they would be willing to be interviewed. Table 8 below shows the number patients interviewed, disaggregated by age and gender.

Table 8: In depth interview participants

Interviews	Total				
		18 -30	31 – 45	46 – 59	60+
Females	7	4	1	2	0
Males	7	4	0	1	2
Total	14	8	1	3	2

The interviews built on the findings of the quantitative health facility survey and were piloted and amended. In line with the Analytical Framework of this study (figure 6 page 77), the topic guides asked the interviewees about their individual health seeking behaviour for their asthma condition, experiences of seeking care in the private sector and also their opinions about how their family view their condition and the wider community thoughts regarding asthma. Due to time limitations, it was not possible to interview community or family members about their opinions on asthma care and the private sector provision of care.

The interviews began with the patients giving an introduction to themselves, their age and covered the 5 main topic areas:

- **Access:** awareness of services and first care seeking
- **Utilisation:** rate and pattern of use of services
- **Demand for service:** health behaviour, reason for seeking health care
- **Perceptions of quality of care:** as a motivator or barrier to service utilisation
- **Health beliefs:** traditional belief systems, shared misconceptions, community

knowledge and perceptions of asthma

Each individual was given a unique identifier number, comprised of a reference number, age and gender. Each quote below is followed by a code that stands for gender (M/F) and the interviewee's age. No two people were the same age and gender. Annex F shows a word cloud of the frequency of words used in the interviews. It was constructed in NVIVO and shows the most common words that occurred in the transcripts,

3.8 Data Analysis of the qualitative interviews

A three-step thematic analysis was undertaken of the qualitative data (Boyatzis 1998). **Step one** was driven by the literature review and theories. **Step two** was driven by my prior research and knowledge of the disease and health care system in Sudan and comparable settings. **Step three** was driven by the data in this study. It combined a deductive approach (Step 1 and 2) and an inductive approach (Step 3). While it can be argued that an inductive approach removes bias and prior conceptions (Boyatzis 1998), it can also be suggested that researchers do not analyse in an 'epistemological vacuum' and therefore bring prior knowledge and experience to analysis (Braun and Clarke 2006). As I have been working in Sudan on lung health for many years, I analysed according to the three steps outlined above and combined prior knowledge and experience with themes developed directly from the data. Key themes were identified through reading of the transcripts.

Interview transcripts were organised using NVIVO software and linked to patient demographics. Concepts and labels were applied using a cross-sectional 'code and retrieve' approach (Ritchie et al., 2013). This gave a systematic overview of the scope of the data and enabled me to make comparisons and connections. I used the computer assisted qualitative data analysis software NVIVO (CAQDAS) to help organise and manage the transcripts and to 'code and 'retrieve' to label sections of text. My first activity was to familiarise myself with the transcripts to give a broad overview and note down strong comparisons and connections (coding). I then developed a thematic framework which arranged the themes into categories, grouping smaller themes together under broader headings (Ritchie et al., 2013). I applied this framework to the data and looked for interconnections between the themes. As my analysis progressed, I revised and amended the framework to ensure it was comprehensive. Once the data were coded, then I developed a thematic chart to summarise the content of the data while trying to maintain detail and richness. For the most part, the findings reported against these themes and quotations were selected as they appeared representative of most respondents or of a particular subgroup of respondents (gender, age group). Some quotations that had an opposite view were also reported as it was felt this showed a breadth of response.

In order to check the reliability of the coding, a colleague coded three of the transcripts, a young male, a young/ middle age female and an older male. I then compared these codes with those of my own for the same set of transcripts. I reviewed the level of agreement (type of code and frequency). As there was a high

level of agreement, I felt that I could apply the coding system across all of the transcripts.

3.9 My positionality

As a white, relatively wealthy, non- Muslim, well-educated woman from the UK, I am aware that when I am working in Sudan I am treated differently to members of the Sudanese research team and that my presence could influence results. I have worked for many years in Sudan through my work at the Liverpool School of Tropical Medicine and in other Arab countries and so feel I have a good level of understanding of the different cultures and ways of working, however, I will always remain an outsider. As an outsider, I accept that I will not fully comprehend many aspects such as the culture, history and identity of the project participants. However, this also presents an opportunity to offer a different perspective, one based in a wider knowledge of health care systems theory and practice.

'It is not possible to conduct research about developing countries without carrying a lot of what is probably best referred to as 'baggage' (Sumner A (2008) page 9).

I also was aware that as the instigator of the research, I had a position of power with the research team. The outcomes of individual interviews by research team members could potentially have been affected by my positionality as the initiator and facilitator of the research. For example, although I encouraged research team members to be frank with me when updating me on the interviews as well as informal discussions, it is possible, and indeed likely that they would put a spin on

their interpretations of how the interviews went, which they judged likely to please me, particularly when discussing health care system issues and the value of the research to them. We discussed this issue in the pilot and training and the team were encouraged that I was not expecting any 'right' answers or that the experiences described needed to fit neatly with the aims of my thesis.

I work as a Senior Programme Manager at the Liverpool School of Tropical Medicine (LSTM) and have worked on joint projects with EPILAB Khartoum (the research organisation that hosted my PhD field work). The projects that we have collaborated on have focused on informal providers for TB outreach, child marriage and latterly a prevalence study on lung disease. It is possible that this close partnership could have influenced the data collection team who were keen to maintain this positive relationship but it was felt that the risks of this were outweighed by the need to work with a Sudanese organisation who could support and navigate the complex political situation in the country. This role at LSTM was also a strength as my experience of working in developing countries for many years enabled me to adapt to the challenges of conducting research in complex environments and to look for solutions and strategies for overcoming the issues.

3.91 Ethics

The project was submitted to the Ethics Committees of Lancaster University (as lead research organisation), Liverpool School of Tropical Medicine (who are contributing funding to the project), and to the National Health Research Ethics Committee (NHREC) in Khartoum. The data collection did not proceed until approval had been

granted by these three committees. Other than minor comments regarding the content of the patient information sheets, all three Ethics Committees agreed on the contents of the application and were satisfied with the research protocol. Annex B contains copies of the Ethical approval from each institution. All of those involved in the data collection, translation, and transcription signed a written agreement on ethical and confidentiality issues. The procedure for conducting the data collection followed the following steps:

- Briefing the study participants orally about the objectives of the study, purpose of the interviews and questionnaires, and procedure and benefits
- Each participant was given a printed participant information sheet that they could keep and refer to if needed
- Study participants were informed about their freedom to choose to participate in the study, and that they can stop at any time
- Informed consent was obtained from all participants
- Permission to record the interview was sought from the study participants
- Storage of interviews and questionnaires were password-secured to ensure privacy and confidentiality of participants
- Reporting of findings did not reveal identities of participants

The survey was conducted with health personnel and it was estimated to take 20 minutes. The aim to keep the survey quite short as it took place during working hours at health facilities and it was hoped that a shorter survey would impact less on

waiting times and patient care. The research team discussed with the health workers as to the most convenient time for the survey so as not to incur a time burden on patients or health staff.

If a patient voiced a concern about mistreatment in their interviews, or if there was a suspicion of malpractice, then the research team would have reported this to the senior local research supervisor at EPILAB (Professor Asma el Sony). She would then have followed local procedures and reported any issues to the overarching medical council within the Ministry of Health. Fortunately, this did not occur and no concerns were raised.

No key ethical issues arose during the research process and the potential risk areas of the studies such confidentiality of the patients and the content of their interviews were secured and there were no data leaks or weaknesses. The quantitative data was password protected and could only be accessed by myself and the research team. The qualitative interviews were anonymised during analysis. The team and translators signed confidentiality agreements. During the period of research, there was some civil unrest in Khartoum and so security of myself and the research team was a primary concern and it did lead to a short delay when interviews could not be safely conducted. However, the unrest was fairly short lived and activity in Khartoum quickly returned to normal and so the team advised me that it was safe to continue.

Chapter 4: Findings

4.1 Chapter summary

“There is a complex relationship between health seeking behaviour, the health of the individual, the material, human and social capital of a community, and the health system” (MacKian, 2003)(page 22).

This chapter presents the findings of the quantitative health facility survey and the in-depth interviews with asthma patients in line with the mixed methods sequential design of the study. The health facility survey aimed to identify the type of asthma services available in private hospitals, health clinics and pharmacies in Khartoum. It also asked the health professionals surveyed for their opinions on how and when asthma patients seek care. The in-depth interviews present the experiences of asthma patients of their asthma care, their use of the private sector and their perspective of the broader social and cultural views with respect to asthma care in the community.

This chapter is structured according to the analytical framework (figure 6, page 77) and will present the findings according to the research questions that were identified from the literature review. The key models used to design and focus the research were Peters and Garg’s model of assessing access to health services, Grundy’s model of health seeking behaviour (individual, Socio-Cultural and institutional) and the Social Ecological model of the multiple levels influencing health care behaviour

(Grundy & Annear, 2010; Peters et al., 2008; Shahabuddin et al., 2017). The findings presented below illustrate the similarities and differences that were found between the interviews and the findings of the health facility survey. Descriptive statistics are used to present the findings of the quantitative survey. Quotations are used to support and/or highlight the explanation of the qualitative findings. Quotations are rendered verbatim and each quote details the gender and age of the participant. This chapter presents the findings of the Phase 1 quantitative survey first and then the Phase 2 qualitative findings in line with the sequential study design.

4.2 Findings: Exploring provision of services from a health system perspective

4.2.1 Availability: levels of trained asthma health workers, asthma drugs, registers, guidelines and asthma diagnostic equipment

The health facility survey gave an insight into which asthma diagnostic and treatment services were available in different sectors of the private sector in Khartoum. The International Guide for Asthma Care outlines a recommended package of care for asthma management (El Sony et al., 2013) . The Guide outlines that Asthma services offered at health facilities should be a package of diagnosis, treatment with inhaled drugs, use of asthma specific registers and staff should have asthma management training. The survey contained specific questions about each of these services.

4.2.2 Range of Asthma services available

The broadest range of asthma services was offered (unsurprisingly) at the hospitals.

6 of the 21 (29%) hospitals offered the full range of asthma services, as

Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in 105

recommended by WHO, including outpatient clinics, diagnosis, drugs, clinical assessment, prevention services and health education. Just over half, 11 of the 21 (52%) hospitals offered the same package but without diagnostics. The remaining 5 (24%) hospitals offered the package of services but without preventative services. The definition of preventative services was a bit vague and mostly centred on health education.

The clinics operated on an outpatient basis and all offered diagnosis, clinical assessment and health education services. Only 1 of the 7 (14%) clinics surveyed also offered asthma drugs. The rest referred the patient to pharmacies for their prescribed drugs.

All the 44 pharmacies surveyed offered asthma drug services and 6 (14%) also offered said they offered health education services but there were little details about what these consisted of.

4.2.3 Asthma registers and guidelines

Asthma-specific registers and guidelines were in low supply in all of the facilities.

Only one hospital and one clinic reported using an asthma specific register and none of the pharmacies kept asthma registers. Asthma guidelines were more widely held at the facilities with 14 of the 21 hospitals reporting that they did have asthma guidelines with most these having been developed at the Ministry of Health. At clinic level, 7 of the 9 clinics had asthma guidelines which were mostly developed outside

the Ministry of Health by other organisations. Only two 2 of the 44 (5%) pharmacies reported having asthma guidelines.

4.2.4 Asthma specific training

The health workers surveyed at the facilities all received training themselves on asthma as part of their general medical or pharmacy training, but of those surveyed, only 4 of the 21 (19%) health workers at the hospitals and 3 of the 9 (33%) health providers at the clinics had undergone specific training on asthma since qualifying from medical school. One pharmacist reported asthma specific training which was carried out at Khartoum hospital. The hospital health providers' training focused on asthma management in the emergency room and as an acute condition. The doctors at the clinics had a broader training on lung function tests and inhaler technique.

4.2.5 Diagnostic services

According to the International guidelines, asthma diagnosis is conducted using a peak flow meter and clinical assessment (Beasley, 2011). Only 7 of the 21 (33%) hospitals reported having a peak flow meter and despite the large numbers of staff, 6 of these (29%) only had one device (with one hospital reporting owning 2 devices). The numbers were higher at the private clinics. Of the 9 clinics, 7 had peak flow meters (78%), the largest clinic (with 25 staff) had 10 devices, 2 clinics had 2 devices while the remaining 4 (44%) clinics had one device each. Spirometry can be used for asthma diagnosis but it tends to be more helpful in understanding other lung health conditions that can often be disguised as asthma (Ahmed et al., 2017). Few of the

hospitals, 6 of the 21 (29%), had spirometers, with one hospital owning 6 spirometers, another hospital had two while the rest had one per facility. Again, the clinics were better equipped and 7 of the 9 (78%) clinics had spirometers (each with one per centre). One centre had neither device and reported that it did not do diagnosis other than by clinical assessment. None of the pharmacies offered diagnostic services and so did not have peak flow meters or spirometers.

4.2.6 Availability, type, and price of essential asthma drugs

All of the 21 hospitals and 3 of the 7 (33%) clinics said that they stocked asthma drugs. However, a weakness of the hospital and clinic surveys was that the detail regarding the type of these drugs and the price was not available. Therefore it was not possible to know if these facilities stocked both the inhaled preventer and relievers as recommended by the International guidelines (Beasley, 2011). All the pharmacists reported stocking a range of asthma drugs. 34 of the 44 (77%) pharmacists reported stocking all 5 recommended asthma drugs (anti-inflammatory drugs, bronchodilators, beclomethasone, salbutamol, budesonide). There was a large variation in the cost of the drugs between pharmacies as listed in Table 9. This is mostly due to a difference in branded and generic versions of the drugs; branded, especially international brands have a far higher cost than Sudanese generic drugs. Mean daily salary in Khartoum is 122 Sudanese pounds, the mean price of the reliever inhalers was around 20% of a daily salary while the preventer inhalers were between 35% for non-branded types rising to over a day's wage for the branded versions drugs (Numbeo, 2017).

Table 9: Prices of asthma drugs

Drug	Price Range (Sudanese pounds)	Mean Price (Sudanese pounds) (standard dev)
Anti-inflammatory	2 – 50	12.87 (15.98)
Bronchodilator	4 -90	26.17 (13.96)
Beclomethasone	3 – 168	42.60 (49.94)
Salbutamol	5 – 42	25.34 (10.60)
Budesonide	25 – 260	124.69 (82.63)

4.2.7 Facility opening hours

The hospitals were all open 7 days a week, 24 hours a day. The clinics had shorter opening hours as they did not have emergency care facilities and saw people on an outpatient basis. Five of the nine clinics were only open in the evening while the other 4 were only open in the morning. When this was explored, it was because these clinics were privately owned, usually by the chest physician who had other responsibilities such as working at hospitals or teaching medical students. Four of the clinics only had one member of staff and the large clinic had 4 staff members. This contrasted with the hospitals, which were much larger and staffed by over 100 individuals. 17 of the 44 (39%) pharmacies surveyed were part of a chain of stores and 27 (61%) were independently owned and managed. All the pharmacy chain stores were open for a minimum of 12 hours a day, 7 days a week. Most of the independent stores were also open for long periods of the day opening at 5 or 6 am and closing 8 or 9pm. 4 stores (9%) were only open in the morning. 1 (2%) pharmacy

was only open 5 days week, 10 (23%) open 6 days a week and 33 (75%) open 7 days a week. The mean number of staff in the pharmacies was 4.5 and staffing ranged from 1 – 9 between the stores.

4.3 Accessibility: Understanding the rate and type of use of services by asthma patients

While it was difficult to obtain exact numbers of patients without referring to many different facility registers (outpatients, hospital inpatients, pharmacy drug records, and clinic records), the health providers were asked to provide an estimate of the number of asthma patients that they had seen each month using recall. In order to obtain accurate numbers, the facility registers would have to have been analysed and then checked for quality. This would have been extremely time consuming as most facilities including some of the larger hospitals still use a paper-based registration system. In some hospitals, there are separate registers for the emergency room, outpatients and for scheduled inpatients so the task becomes very complex. Relying on the health providers is open to bias, especially recall bias, but it does give a sense of the scale of numbers of asthma patients who use that facility. For this research, the range in the numbers of people who use the different types of facilities highlights how varied the different facilities were in size and patient number. There was a very large variation between institutions, which demonstrates how diverse the private health sector is in Khartoum.

Table 10: Estimated mean number of asthma patients per month at each facility level

Facility type	Number of asthma patients per month Mean and range (Standard dev)	Number of asthma patients who visit the facility repeatedly Mean and range
Hospital N=21	116 (122) (2 – 450)	37 (38) (1 – 120)
Clinic N=9	61 (40) (16- 150)	38 (27) (3 – 80)
Pharmacy N=44	57 (94) (4 – 600)	19 (27) (0 – 120)

Table 10 shows the estimated mean number of asthma patients who visit the facilities each month and an estimation of whether they are repeated visitors or newly diagnosed patients. The figures show that most asthma patients visit the hospitals, with a mean number of asthma patients per month of 116. There was a large range in the numbers of asthma patients seen from 2 per month to 450. Clinics and Pharmacies saw a similar mean number of asthma patients per month (61 and 57 respectively) but the Pharmacies had a greater variation with one Pharmacy seeing 4 asthma patients per month while another (based at the large private Khartoum hospital – included in this study) saw 600 asthma patients a month.

The Pharmacies and Clinics both reported that they saw far more adult asthma patients than children. For Pharmacies, it is possible that the adults buy the medicine

for their children and therefore it is difficult to gauge this more clearly. Hospitals reported more children visiting than adults but this difference was not large. The Hospitals and Clinics reported similar rates of men and women attending their facilities. Pharmacies reported far more men visiting their facility and again there is the possibility that they are purchasing the drugs for their wives and female family members. These aspects were explored more fully in the qualitative phase of the research.

The health providers were also asked to estimate how often their patients sought care for asthma in a year. They were asked of those who were repeat visitors to their facility, how often did they seek asthma services per year. The health provider routinely collects this information from a patient during a consultation, and they were therefore asked to draw on their experience of treating asthma patients. There again was a large variation in the answers but on the whole the figures were high with hospital providers estimating an mean of 18 visits per year, clinic doctors estimating 8 visits and pharmacists estimating an mean of 17 visits per year. The reasons behind these very high figures of repeated visits were asked about in much more detail in the qualitative work with the patients.

4.4 Acceptability: Provider perspectives of the health-seeking behaviour of patients who use the private sector

The health providers surveyed were asked about their perspectives of the health-seeking behaviour and pathways of patients who choose to seek care in the private sector.

18 of the 21 (86%) health providers surveyed at the hospitals reported that hospitals were the first point of seeking care for their asthma patients with the majority of those specifying that the emergency room was where most people went. The remaining 3 (14%) of the hospital doctors reported that the nearest health centre was the first point of care seeking. When asked why the providers thought that the hospital or emergency room was the first point of care for their asthma patients, 15 of the 21 (71%) health providers thought it was because their patients only sought care when their asthma was an emergency.

The doctors at the 9 clinics gave a very similar response with 8 of the 9 doctors surveyed reporting that the hospital was the first point of care seeking for their asthma patients with only 1 (11%) reporting that the health clinic was the first point for their patients.

The pharmacists reported a broader range of point of first contact, 25 of the 44 (57%) pharmacists reported that the hospital was the first point of contact for their asthma patients, 13 of the 44 (30%) reported that the pharmacy was the first point of contact and 6 of the 44 (14%) reported that their patients usually went to their nearest health centre first. It is possible that patients who visit the pharmacy as their first point of care seeking have less severe asthma or whether the visits were pre-diagnosis, but the survey did not capture this information. These aspects of care seeking were followed up in the qualitative interviews with the asthma patients.

The last part of the survey asked open ended questions to the health providers on their opinions as to why some of their patients might not take asthma medication routinely and whether this was a factor in the high numbers of repeated visits. There was a big variation between providers' responses at the different facility types. The majority of pharmacists (17 of 44 (39%)) suggested cost was the main limiting factor. Almost half of the Hospital providers (48%) felt that patients stopped using preventative treatment if they had a long period of time between attacks or that patients felt better, suggesting patients regarded the attacks on an individual basis that required care rather than an on-going condition that required monitoring. Table 11 below gives the detail of responses given.

Table 11: Reasons suggested for not continuing long term preventative treatment

Reason given by the provider	Facility level		
	Hospital Providers 21 respondents	Chest Clinic Doctors 9 respondents	Pharmacists 44 respondents
Cost	2/21 (9.5%)	3/9 (33.3%)	17/44 (38.6%)
Felt Better/ Long time between attacks	10/21 (47.6%)	2/9 (22.2%)	6/44 (13.6%)
Did not accept diagnosis	1/21 (4.76%)	0	3/44 (6.8%)
Lack of availability of asthma drugs	0	0	3/44 (6.8%)
Low understanding of diagnosis	5/21 (23.8%)	2/9 (22.2%)	3/44 (6.8%)
Worry about long term inhaler use	2/21 (9.5%)	1/9 (11.1%)	0

These responses were helpful in guiding the topic guides for the qualitative phase of the work. The health providers surveyed were chosen as they have direct contact on a very regular basis and therefore on the whole do have a good sense of their patients' health-seeking behaviours and their care pathway. However, Socio-Cultural influences such as issues of stigma, community interaction, traditional beliefs were not included in the study as it was felt that short survey style answers would be

difficult on this topic and that further explanation would be needed. Therefore, questions regarding these influences were included in the qualitative work.

4.5 Findings: Exploring the perspective of individual asthma patients

4.5.1 Access: symptoms, awareness and first care seeking

The process of choosing one provider over another requires an individual to recognize their illness, perceive a need for care and then be able to access the services that are needed. This step by step process is outlined as the pathway to care (Levesque et al., 2013). In order for the patients to reflect on their pathway to care, the asthma patients were asked to describe their experience of being diagnosed with asthma and how their pathway to care had evolved since first feeling the symptoms. Most of the interviewees described their symptoms as starting as a cold or infection that progressed to asthma.

‘By God, I was very young, my mother told me that I was very very sick and having something like an infection, after I became older I didn't get any of these infections thanks God. After I became 20 I got a severe infection, meaning that after 20 years I have discovered that I have Asthma’. (F36)

As the quote above demonstrates, early symptoms were often diagnosed as other conditions and that the asthma diagnosis often came much later once the disease was severe and urgent medical help was needed. This is consistent with the findings of the health provider survey that highlights that most of the cases seen at hospitals

and clinics are at the level of needing emergency care. One young woman (aged 18) described that she started coughing and then suddenly lost consciousness. It was only after this severe attack was she diagnosed as having asthma. The quote below highlights that the initial symptoms were initially dismissed as infection and then a severe attack took place that needed hospitalisation and there a diagnosis was made.

'Yes, I used to have infections, almost every month. I used to take a lot of antibiotics so that the illness goes away. But in 1994 exactly I had an attack of complete breathlessness. I was in the dormitory, the boys carried me to the clinic. In the clinic, they referred me to the general hospital here in Khartoum. In Khartoum, they started to put me on ventilation machine, they gave me injections in my arm. This was the first time I discovered that I have asthma for life'. (M48)

All the interviewees were asked how they were diagnosed with asthma and whether any specific tests were used but only one person described being diagnosed with a peak flow meter or spirometer. The rest either described doctors giving the diagnosis based on the symptoms or self-diagnosis based on their knowledge of the disease usually due to family members having the disease. This is consistent with the low levels of diagnostic equipment found in the health facility survey especially at hospitals. Lack of a clear or early diagnosis leads to a more complex pathway to care with multiple visits to health providers needed before the appropriate treatment (in this case inhalers) can be prescribed (Peters et al., 2006). Asthma is a complicated

disease to diagnose as there is not a simple laboratory or point of care test that can be done to confirm or deny the presence of the disease but the diagnostic tests (peak flow meter and spirometry) do give the physician a depth of information in order to make the diagnosis.

4.5.2 Utilisation: rate and pattern of use of services

According to the International Asthma guidelines (El Sony et al., 2013) , once an asthma diagnosis is made, a patient should receive an asthma management plan. This guides the patient on how to take their medicine, which inhalers to use and how and where to seek care. These plans have been shown to lower the need for emergency care and lessen the number of severe, life-threatening attacks (El Sony et al., 2013). None of the patients interviewed had such a plan and all described very complex journeys to seek care. Most of the patients only sought care when they were experiencing an attack. This care ranged from using a home oxygen kit to having to go to the hospital emergency room for treatment. For some of the patients, the journey meant that they had to seek care outside of Sudan as demonstrated in the quotes below:

‘the first time was a regular allergy, there was no inhaler used or anything. I was only taking regular tablets that I don’t remember the name of, but they were small and red. The sickness got worse and I had to take the inhaler after one year. I think at that time I was setting for my exams for the university. I went out in the rain and the illness got worse until I reached the stage where I was needing an inhaler. When I went to Egypt [as a remedy for asthma]. they gave me hydrocortisone I was initially

following up with a doctor named Sarah at Almonawarha clinic (private hospital), she then transferred me to a big specialist named Eltoraby (private clinic) and he is the one who advised me to go to Egypt just to change the atmosphere so I did' (F30)

'The first time was in 1982, I felt severe tightness and shortness of breath. I remember the first time I went to Mohieldin Mahdi [private clinic doctor], God rest his soul, in Alqasr street. I remember he told me that I have asthma, then he told me I will prescribe 3 injections, he prescribed syrup medication which was Ventolin. This continued until I came back a while later. He changed the syrup to tablets and told me I have asthma. He told me to control the asthma, so in that period from the eighties to the nineties I used to go to the emergency room a lot. Every week or two weeks I used to go to the emergency room in Khartoum hospital. It was near us in Alqasr street, so I used to go and at the time there was no oxygen mask of course. They used to give me an intravenous drip with a big injection and Cortisone. This continues approximately until the year 2000. I went to a doctor in Cairo, he gave me some tests and he told me the asthma is due to dust and animal waste. He told me to control my asthma, he changed the tablets to inhaler, since then I have been using the inhaler'. (M60)

As demonstrated above, the patients seek care repeatedly. This is consistent with the health facility survey in which the number of repeat visits per year was estimated to be very high. Repeated visits affect the patient's ability to live a full life and also

come with high levels of financial costs. This woman describes going to the hospital to receive oxygen five times a month and has to pay each time.

'There is supposed to be discounts as the attack can happen to the patient about two times in a week. And the oxygen room is for 40 pounds, so you can see in a month if I got sick five times and there are people who have continuous repetitive asthma and it is according to each situation. For me it is a continuous asthma and any minor thing can affect me, dust or heavy wind and also if I made a great effort or I got mad because of a situation then I will not be able to breathe'(F30).

In the majority of asthma cases worldwide, the use of preventer inhalers substantially reduces the number of hospital visits (Beasley, 2011) and reduces severity of attacks. A few of the patients interviewed in this study, described using these preventer inhalers but most people only described the use of oxygen and reliever inhalers such as Ventolin. There was no difference in age or gender affecting inhaler use, the common theme was that the reliever inhalers did help and some people reported that they needed to go to the hospital less if they used them.

'the first time, I had a cough and it was a cold weather. It was accompanied by fever and I was having difficulty breathing. I diagnosed myself as a pneumonia. Then I started feeling that I am not breathing very well, so as a doctor I took Ventolin. That was about a year and half ago. After that I found myself to be better and I went to the pharmacy and I bought a regular inhaler. When I feel that I can't breathe, then I

will use the inhaler and I was getting better after that. When I saw that the situation is getting worse as I am working in Best Care Hospital (Private hospital), then I went to Dr. Mawahib who is a Chest physician, she diagnosed me as severe asthma, she gave me Nebuliser and now I am taking Ventolin'. (F28)

Only a few people reported ever having used a preventer inhaler but those that did felt that they were very beneficial.

'Before I came here to Dr. Majdi, I used to suffer a lot, each week I stay two or three days at home until I came to Dr. Majdi. I told him my history with asthma and he gave me the preventer, since then I feel a lot better. I am a completely new person after I started taking the preventer'. (M48)

Cost was cited as a key concern for people accessing care. The cost of both types of inhaler was highlighted as a major reason that people did not use inhalers. All the patients interviewed described how expensive asthma drugs were. Prices that were quoted varied depending on the type of inhaler, and whether it was an imported brand (70 to 100 Sudanese pounds (SGD)) or a local brand (30 SGD) for reliever inhalers. Preventer inhalers ranged between 200 to 300 SGD. These figures were consistent with the health facility survey where a large range of costs for asthma medication were reported with branded medication and preventer inhalers costing far more and varying between facilities substantially. While for some people the high costs meant that they would not use the inhaler, others reported that they would

prioritise affording it over spending money in other areas as demonstrated by the quote below:

'By God it is not good, but thanks God what can we do about it, everything is becoming very expensive and this [inhaler] is the only thing that has to be always in my hands and I can stop eating or drinking, but the inhaler has to be in my hands'
(F36)

There were a lot of costs reported in addition to the price of the inhalers, such as the use of the oxygen room, injections, hydrocortisone, and doctor consultation fees, and these were considered as barriers to sustaining effective asthma management.

'first of all, I will take three shots of oxygen for 40 pounds and it is just a normal room that has oxygen. To see the doctor is for 25 pounds and I buy the hydrocortisone injection with my own money, but at the Algalea centre (public health centre) the bed is for 20 and the doctor is for 20 pounds and they will give you the injection for free and it costs 7 pounds'. (F30)

These findings that cost was an important concern for patients were consistent with the health provider survey where a large number (39%) of the pharmacists cited cost as the main reason people would stop obtaining asthma treatment.

Another person reported that he often saw a person begging on the street outside an asthma hospital asking for inhalers, and sometimes he would try and help by buying an extra one.

'I saw people who beg for the inhalers in Hawadith street, he brings the receipts and tells you that he wants an inhaler because his inhalers are finished. Sometimes I buy it for him and other times'...(M60)

This quote highlights two main things: firstly, that some people's demand for an inhaler is so strong that they would beg for it when they cannot afford it and secondly, the costs of these inhalers are completely out of reach to some sections of the population. A weakness of the interview is that was not clear whether this man wanted an inhaler because his asthma was so severe and whether he had received doctor's advice to use one in the past, but clearly he thought it was so important that he would ask strangers for money for it.

4.6 Demand for service: health behaviour, reasons for seeking asthma care

4.6.1 Family history of disease

Many people reported that inherited factors played a key role in their asthma condition, and that this was the main causal factor of their condition. Genetics and family history was mentioned by over half of the patients, as demonstrated by these quotes:

'the asthma that I have is something that I got from my father as he got it because of his traveling. Now my brother and I are having it. My family is made of 14 members and they are all well except for the two of us'. (F30)

While this quote could imply that they felt that asthma was contagious, the Arabic translation of 'got' implied that they felt genetic factors were the reason that they had asthma.

'Now I have a small daughter and she has asthma, they give her Ventolin. She has inherited it from me and she got the attack many times so this is why I am worried'. (F55)

'There is no problem in the family, we are in an asthma forest, my mother, grandmother and uncles have asthma. So this is a very normal thing in because it already exists in the family.' (M48)

These quotes demonstrate that the belief that asthma was hereditary was not gender specific and was held across the age groups. It led to a sense of feeling that there was little that could be done about the disease and that they should just accept living with it. The belief that asthma is hereditary is so strongly held that one young woman described the shock of being the only person in her family diagnosed with the disease.

'By god the people of my house were very shocked, to be frank with you, the shock for them was abnormal as there is no asthma in the family. We have not anyone having asthma in neither my father's nor my mother's side... Of course we went all and when

they were told it was asthma, then they said where has she got this illness from? At the end of course they can say nothing as it is from God almighty.’ (F36)

4.7 Knowledge of others with the disease

Many people described how they knew someone (a friend or neighbour) with the disease, and it was thought to be very common.

‘Nowadays you will never find a home that doesn’t have one who has asthma in it. it has spread and even many children have Asthma. You will find many children having asthma that has started in them and when they go to the doctor they will prescribe them the inhaler. Back in the days the inhaler was the last resort, but nowadays it is a common and normal thing.’(F54)

4.8 Severity of disease

Severity was a theme that came out strongly across many of the people interviewed and was consistent with the health facility survey that highlighted many people sought care when their asthma was urgent and life threatening.

‘Asthma puts you in a bad psychological state, you confront death, this is the only disease that makes you feel that you are about to die. And when you are treated you will be in a very bad psychological state because the asthma patient is always stressed, whether he has an attack or not. He can get an attack at any time. This is why I think the asthma patient is always at the edge of his life...’ (M48)

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'Sometimes I will stop breathing and the asthma is a disease that attacks suddenly and it can cause death. There are doctors who will consider the seriousness of the situation'. (F30)

'I mean seriously this thing was a big obsession for me; it is a fatal disease and should not be taken lightlyLike I gave up on life, I will not lie to you, it is like you find out that you will die soon, it is in God's hands' (F30) (after being asked how she felt when she received her diagnosis)

'Asthma is a serious disease and there are many people who don't take it seriously and there are many who die because of it simply because they come late or because of carelessness' (F18)

The quotes illustrate that the association between asthma and death is strongly held and by a broad range of age groups and across both genders. This affected choice of provider as care was sought urgently in an emergency setting rather than as routine management of the condition. In many countries, asthma is not viewed as a life-threatening disease but a chronic disease that can be managed. In Sudan, these patients all described their fear of asthma related death and how they focus on treating their attacks as a series of acute episodes rather as a chronic condition. Accessing care and provider choice for acute attacks can be quite different to long term management of a condition. The majority of people sought care because they were extremely ill, and therefore the decision as to which facility to seek care in was not made by the patient, but by someone else (a family member or neighbour).

'they lifted me up as I was completely comatose, and I was not breathing at all so my family supported me and they started shouting and the neighbours came and helped with lifting me up, our neighbour took me in a rush to the hospital' (F36)

4.9 Impact of the disease

The impact asthma had on the patient's daily life was strongly articulated, with most people (men and women) describing high levels of worry and concern.

'Worry is an understatement...Asthma puts you in a bad psychological state, you confront death, this is the only disease that makes you feel that you are about to die. And when you are treated you will be in a very bad psychological state because the asthma patient is always stressed, whether he has an attack or not. He can get an attack at any time. This is why I think the asthma patient is always at the edge of his life. He has things he wants to achieve but cannot for a simple reason which is psychological.. there are a lot of plans that the asthma patient postpones. The physiological impact is dangerous, it hinders a lot of plans. This is the most dangerous thing about asthma, it disrupts your life.' (M48).

Others described how it disrupts their plans and is an obstacle to carrying out a normal life.

'My feeling was extreme anger because he [the doctor] forbade me from playing football and grasshoppers and dust and such. I used to work with my uncle during the

holidays as a building labourer, he forbade me from all of that, I just sit in the house, bored' (M29)

'Sometimes I would find myself collapsing because I got tired but I can only thank God. I have stopped from my studies. This illness needs follow-up and to know how to know the use of the medication' (F30)

"I am scared and worried when I have an infection, I will not be awake, not among the living and not among the dead' (F36)

One older man was an exception and reported that he was not afraid of asthma and that he practised sport normally. On the whole, the younger age group (both males and females) described higher levels of concern about having the disease and that it majorly impacted on their daily lives causing them to stop doing certain activities.

4.91 Self-management of their disease

The literature on self-medication found that it was most closely associated with women, those with a low monthly income and of middle age (Awad et al., 2006). However, this study did not find strong gender differences with both men and women describing managing their asthma themselves. Age did seem to be a factor with more people mentioning self-medicating who were over 30 years old and only a few under 30 years.

It was clear from most of the patients that they managed their asthma themselves and did not have a treatment plan that was monitored by a health professional despite this being a key recommendation of the International Asthma guidelines.

'It has been years since I saw a doctor...I just use my inhaler. I control my asthma and avoid infection and flu. Last time I saw a doctor was in 2000/2001' (M60)

'I work in a hospital so take oxygen when I feel sick. I know my medications so I take them on my own. I did not go to see a specialist'. (F30)

'the thing that really make me stressed is when I get an infection which will make me literally run to the hospital. when I don't have an infection, I will use the inhalers normally and sometimes I would go to the pharmacy and bring the injection by myself and I will be given the intravenous injection. They will give it to me in a drip and it takes about half of an hour and when it finishes I will be alright.' (F36)

People also described how they bought oxygen for use at home so that they could manage their attacks when they occur and avoid having to go to hospital.

"I had to buy an oxygen machine as I get attacks continuously. I got fed up with doctors. The last doctor I saw was 7 or 8 years ago. I consult my brothers instead.' (M48)

Buying an oxygen machine has a considerable upfront cost, it was viewed as a more effective way of treating the attacks but does not offer any preventative therapy (as inhaled steroid medicine would) and therefore does not assist in reducing the

number or severity of the attacks. One man did describe using a neighbour's oxygen machine in conjunction with self-prescribed medicine and that combination was viewed as a way of managing his condition.

'One of our neighbours has a device [oxygen machine] so I use that. It has been years since I went to a doctor. I just get medicine from the pharmacy' (M60)

Many of the patients interviewed used alternative therapies to relieve their asthma. The same traditional remedies used were described by several people and while most did not see these remedies as alternatives to western medicine, they did feel they offered relief from the symptoms.

"You always hear about the herbs and black seed, honey, and dates. You mix them and take them in the morning. People use that. ... They used to think there was no treatment for asthma and that is why they start relying on [herbs], and better that you use something, herbal and a lot of people use them." (F54)

'I used honey. They used to prepare me honey with black cumin, it was and original honey added to it grounded black cumin. I used to take a spoon early morning and another at night, however, it is the inhaler that is faster. At any time that you are not breathing well you will use the inhaler and you will be better much faster than the honey treatment'. (F55)

'I have once used the honey. I used to have it to treat my stomach and I have felt that it helped me with the asthma very very much. I didn't have an attack in the time that I was using the honey at all. Asthma didn't come to me for a very very long time. I

remember it was a big bottle that I was using and it was about two pounds or so, but I used it for a very long time, three or four months and Asthma didn't come to me at that time' (M60)

They reported that the remedies they used were self-prescribed and recommended by families rather than by a healer or traditional doctor. Traditional doctors are still commonly used in Khartoum and more widely so in rural areas (Awad et al., 2005), none of the patients interviewed reported visiting them. It is possible that this area of interest was not probed in enough detail or that asthma is not viewed by this group as something these practitioners help with.

4.92 Use of medical insurance

All the people interviewed understood that medical insurance existed and could cover treatment costs (only a few described using it well), and that it either completely covered their asthma treatment or substantially reduced the costs. Others described how they had insurance in the past but changed jobs or retired, and so no longer had it. Some described losing their insurance card and it was difficult to get a new one, whilst others explained that asthma was not covered in their insurance, and therefore had to pay the full price. Medical insurance is still not common in Sudan though it is increasing in cities where people either have it as part of their salary package or they purchase it individually. Most people however, do not have health insurance and so pay for their asthma care on an out of pocket basis.

4.93 Perceptions of quality of care: Key factors that patients give about seeking asthma care in the private sector

The patients interviewed were asked to identify the main reasons that they sought asthma care in the private sector. The participants gave details on their perception of differences between the public and private sector. Most patients reported that the main difference between public and private care was that the public sector facilities were very overcrowded. They reported that they would often have to wait a long time for an oxygen machine as there were often two or three people waiting for each machine.

'The public hospitals are crowded. Eight or ten years ago I went to Alnaw, when I went I found they have one oxygen machine with Ventolin. I wait because there are two or three people in front of me. In that moment you will be annoyed but in the private hospital, in Elgazira or Disoogi centres, they have a number of machines and beds. One of our neighbours, a physiotherapist called Abdelmagid, has one at home'
(M60)

In addition to overcrowding, the availability of working oxygen/ Ventolin machines was also highlighted as a problem in the public sector. This man outlined the serious consequences that could arise from a lack of medicine, machines or staff.

'There is no comparison, you can enter a public hospital and find no machine there, this is very common. I think there are a lot of asthma patients who died because they find the Ventolin machine non-functioning for example. In any public hospital, you can be sitting down and they come force you to leave... You can go to a public hospital and surprisingly you find that the machine is not there or that the nurse or person responsible for putting you on the machine is not there. Or you can find that the liquid drug is not available.. The liquid might not be available, you can wait for 10 or 15 minutes or half an hour, this is enough for you to depart from this world' (M48)

Some people described having to wait two hours in the public sector to see a doctor. The private sector on the other hand was reported to have many more machines which were much newer, and there was a shorter wait to see a doctor. These were the key reasons that people gave to why they chose the private sector over the public sector. However, the doctors at private clinics were criticised for being only interested in money, and often not having a lot of asthma specialist experience. One patient did comment that at one private facility there was no machine and she was referred to a public facility but this was an exception. In addition to the lack of trained doctors at public facilities, there was worry about the hygiene levels found at some public facilities as demonstrated by the quote below:

'when I am tired and out of breath they will take the mask out the patients' mouth [at public hospitals] and then they will give it to you immediately without being

washed....Even if you were stressed they are supposed to sterilise the masks, they will immediately take it from me and will give it to another' (F36)

Public hospitals were often described as not being clean enough and chaotic when compared with private facilities and this was a motivating factor for not seeking care in the public system.

Other patients reported that they did not have confidence in the public facility staff, especially when being treated in emergency rooms. One patient reported that in a public hospital, the nurse did not know how to give injections and only did so correctly after three attempts and would only inject once the medicine was bought from an outside pharmacy and brought in. This relies on the asthma patient either being well enough to buy the medicine before starting treatment or coming to the emergency room with a family member who can go off, locate and purchase the medicine.

'Some of the nurses [in public hospitals] don't know how to give injections, I came a number of times and the nurse gives me the injection correctly after 3 trials.. sometimes someone comes without money even for an injection, not even the empty injection, no one will do anything for him.. there's an injection written on this paper.... I will go bring it now from outside for 20 pounds but I have to bring it from outside'.
(M29)

The interviewees described situations where doctors and pharmacists prescribed or gave treatments but did not demonstrate how they should be used. This was especially the case for inhaler use, where the difference between the two main inhalers (preventers and relievers) was often not known. This left many patients, especially the younger patients, feeling that they required more information on how to use inhalers and what the purpose for the different inhalers were.

'At the time I went to him he gave me three kinds of inhalers, when I went for the first follow up he made them two inhalers and when I went for the second follow up he made them one and continued with this one... By God, he explained to me about what is it for, but I can't remember by God, Of course they are better than us in these things, and after that I just have only this inhaler' (F36)

'the pharmacist when he gives you the treatment they will not explain you how to use the inhaler, they will only sell it to you. Also the doctor will prescribe it and will not tell you how to use it. Some of the doctors will do that, they prescribe you an inhaler and they will not show you how to use it' (M60)

This participant did report complete trust in their practitioner but also demonstrated a low level of understanding of her condition. While most of the health facilities surveyed did report that they undertook health education activities with patients (such as counselling), the patients felt that this was not satisfactory. None of the patients described, when prompted by the interviewer, receiving any health

education materials such as leaflets or guides to asthma which links with their lack of knowledge about the disease and its treatment.

Location was also a key theme affecting the choice of provider. This was varied and depended on the severity of the attack. In a severe attack, the nearest facility was chosen. Proximity of health service was a key factor highlighted by the interviewees:

'this [private] hospital is close to us and they will save me faster. The private hospitals have solved many problems especially for the asthma patient and those who have accidents. The public hospitals are cheap, but there are many things that are not available.' (F18)

Patients also expressed that they would choose a health provider that was known to them and that the private sector was their always their first choice:

'Whenever you want to go to the doctor you go for the private sector... This is the first option you think of. That is somehow the culture. You go for the doctor that you know or one of the family prefers or recommends and you just go pay a visit and that's it.' (F30)

The choice of pharmacies was predominately based on proximity to home. Most people used the pharmacy that was closest to where they lived. Pharmacies vary a lot in Khartoum from fully equipped stores that are part of a big business chain to

those that are family owned and much simpler in style. None of the patients described these factors as affecting their choice of pharmacy.

4.94 Acceptability: Health beliefs held by asthma patients and how these affect their choice of provider, traditional belief systems, shared misconceptions

Whether asthma is viewed as separate acute episodes or a long term chronic condition seemed to influence how people sought treatment and how they perceived it affected their lives. While many respondents acknowledged how common the disease was in Sudan, they often preferred to refer to it as an allergy rather than a long-term condition. The use of the Arabic word 'hassaseer' rather than 'asthma' was an indication about the reluctance to accept it. There was a belief that an allergy was something that could be treated and was short term whereas asthma was a lifelong condition that had social and physical consequences. The patients described that there was a reluctance by health workers to discuss asthma and preferred to diagnose an allergic reaction.

'Even the health workers .. use the word 'hassaseer' [allergy], they start stigmatizing, especially when you find you are a woman who is younger. They say you have a chest hassaseer without using the word asthma....There are people who will hide that they have asthma, there are some who will be shocked and they will say it is allergy.' (F18)

This young woman quoted above would only discuss her symptoms and treatment pathways in terms of allergy and was uncomfortable to say that she had asthma.

Several of the patients said that they had no knowledge of the disease before they were given a diagnosis. The key irritants mentioned by the patients that brought on an attack were dust, cold, anger, and strong emotions. Most patients described their initial symptoms as either an allergy or an illness that got worse and became asthma, as demonstrated by the quotes below:

'they have told me that it started as a pneumonia when I was a child and when I grow up I began to realise then it was allergy and I was sneezing..... We moved here as when the autumn comes and it starts to rain then I get very sick and have difficulty breathing so we moved here' (F55)

'My father used to take me to doctors and they say it is infection and allergy and they give medications for normal infection' (F30)

Several different causes of the disease, and the triggers that can result in an attack, were given and these ranged from stress to pollution and tiredness. Treating asthma as an allergy meant that many of the patients, especially female ones, only sought care when they had an attack and were more comfortable about taking allergy medication rather than asthma management treatment.

The stigma regarding an asthma diagnosis extended to stigma regarding the use of inhalers in public and this was highest for younger women. Many of the younger

women interviewed reported that they would rather not use their inhaler when in public, and that if they did, it would bring unwanted attention, as illustrated by the woman below:

'By God, frankly doctor when I got this disease and they gave me the three inhalers, I was very sensitive and I was not able to carry my inhaler with me. One day I travelled with my mother to Kosti to visit my uncle. As we were going out and she was telling me to take my inhaler and I was very sensitive about this issue, so I told her that I can't take the inhalers. Do you want me to puff in front of all the people? So I said I will never puff in front of people. Because I felt that all the people were looking at me and I was very shy about this issue, so she went back and took the inhalers and put them in the bag'. (F36)

The International Guidelines on asthma management (Beasley, 2011) outline that two types of inhaler are recommended, one to relieve attacks and one to use between attacks to reduce their severity and occurrence. High levels of stigma regarding inhaler use can have a big impact on the lives of people living with the disease. Not using inhalers regularly means that attacks are often more severe and more dangerous and need hospitalisation.

4.95 Socio-Cultural influences: Community/societal views

The influence of community views of asthma was reported strongly and by many of the interviewees. People reported a low level of understanding in the community of

the disease and how it can be managed successfully. They also highlighted a little knowledge in the community as to the causes of the disease. Many of the patients described how people treat them different when they find out they have asthma. Patients described some of the misconceptions that they had heard regarding their disease, and that this can result in being treated differently by other people.

'People are afraid of asthma because they think the patient will have an asthma attack if he gets into a small argument. But it is the opposite and he is normal like everyone else. – people are afraid of arguing with asthma patients'. (M21)

These commonly held beliefs were not always accepted by the patient themselves but they felt the beliefs were so strongly held in the community that there was little the individual could do to change these beliefs. It often led to a delay in diagnosis and a delay in treatment.

'they didn't tell me it was asthma, they have said shortness of breathing, they have also said it is because I am mad at something and I was not, I was chatting and out of sudden I started to cough and I was not able to breathe, they didn't know that I got asthma but they gave me oxygen, but they didn't tell me that I got asthma...After that incident it kept happening over and over again so we went to the specialist'
(F36)

Others described how having asthma is seen as negative by the broader community and that there is a social stigma towards asthma patients. Both younger men and women reported experiencing this stigma, but it was most strongly felt by younger female patients (30 years and below). The disease was often viewed as contagious, and therefore changed how people were interacted with. They highlighted that their immediate family did not hold these views but the community did view the disease very negatively and that they therefore did not openly discuss their condition.

'Not always and not all of them, except people who are very close to me and there are some people who are scared of the disease they say it's contagious' (F30)

'My family knows about the disease and the costs and they are ready for it, as for the community they will see the asthma as a contagious and disgusting disease, but I see that it is a mistaken point of view'. (F30)

Some of the younger women also reported that because asthma is a long-term condition, people in the community perceive the disease to have a long-lasting impact on the patients' futures.

'there are people frankly when they would approach you for marriage and know that you have asthma, they will be afraid and will say that she will always be taking me to doctors and even the children when they are born then might have asthma because of the weather....if someone wanted to marry you then if they know you have asthma, they will say that she has asthma and that she will take me to the doctor all the time so I better find someone who is healthy. They don't know that illness is from

God and he might find someone who is healthy and she might get sick with him or that he himself will get sick' (F30)

The use of an inhaler in public was also described as something that people were cautious about, particularly younger women. One mother reported that her daughters were viewed negatively when they used their inhaler in public. While the mother knew the benefits of inhaler use, she highlighted that the broader community held stigmatised views of them.

'they do not have any knowledge of the disease, as Sudanese they will ask me why do I insist to say that my daughters have asthma and they refuse and they say that one of them will be addicted to the treatment. All of that is not correct and in contrary if one takes the medication then it will become less' (F45)

While younger women reported the higher level of stigma surrounding public perceptions of their conditions, younger men also described their reluctance to use inhalers in public and that their use was something that they felt embarrassed about.

'the feeling of the asthma is a sensation as if you are lacking something. As if you are missing something and I was earlier telling them that one will be shy to take out his inhaler in the transportation or any other place as you will think of yourself as if you are inferior or lacking something' (M30)

Some patients did describe more positive attitudes from their close family and friends, but these tended to be the older participants, who reported that people were accepting of their condition and were not concerned by it, even when it was serious. These two quotes show how the condition is normalised and that their friends have a level of understanding about its treatment.

'My friends accepted it because they are my friends, they reassure me that asthma is not a problem and it's treatable, the whole of Sudan and the world has asthma.

There is no problem in the family, we are in an asthma forest, my mother, grandmother and uncles have asthma. So this is a very normal thing in because it already exists in the family' (M48).

'yes it is normal, all the people know that I have it. They hear the wheeze and those who know me always buy me inhalers' (F55)

While some people did report that their friends and family knew about the disease, there was the assumption that the community as a whole believed the best method of treatment was treating an acute attack at the hospital emergency room.

'Asthma is known, everyone knows it, people in the bank where I worked know about it, as soon as I get an attack I go sit outside away from the air conditioners. They prepare the car and take me to the emergency room. People understood it and gained knowledge about it. It is very wide spread in Sudan' (M60)

The qualitative data highlights that the stigmatisation of inhaler use is compounded by society's view that the best method of treatment is at hospital emergency rooms.

This fits with the low level of preventer inhaler use amongst the interviewees and their repeated visits to hospitals for acute care.

5. Discussion

This study aimed to gain an understanding of the health-care-seeking behaviour of adult asthma patients who use the private sector in Khartoum to treat their illness. It used a Social Ecological approach to examine the different drivers of private sector provision and utilisation in an urban setting in Sudan (Shahabuddin et al., 2017). The first phase examined the health systems/ organisational level by obtaining information regarding the availability of services and accessibility of services, from a provider's perspective. It examined the provision of asthma diagnostic and treatment services available for adult patients in the private health sector, in Khartoum. Three levels of service provider were surveyed: at hospitals, at specialist chest clinics, and at pharmacies.

The second phase of the research identified the factors that result in asthma patients choosing private health care providers for their treatment. This was a series of qualitative interviews with asthma patients who use the private sector. The focus here was on the community, family and individual levels of the Social Ecological model in figure 5 from an asthma patient's perspective. It explored how and why asthma patients make health care provider choices within the private sector. The sample included a mix of ages and genders. They were asked about the process of their healthcare utilisation, and what main barriers or motivating factors prevailed to influence their choice of provider in a pluralistic health care system such as is found

in Khartoum. This study drew on the strengths of different methodologies to explore access to asthma care.

The quantitative survey enabled data to be collected on the provision of asthma services so that the context of private sector care could be understood (which services are available, where and when). Qualitative methods allowed for more detail on patients' experiences of living with asthma, their experiences in seeking care and their rationale for choosing one provider over the other.

This chapter will discuss the research findings according to the conceptual framework set out in figure 5, page 72. Each layer of the framework describes a level of influence on asthma care seeking and how the different levels interact. As most of the findings of the research focus on the interpersonal and individual factors, the discussion begins with these sections, then expands to the community levels, organisational and health policy factors.

5.1 Interpersonal or family factors

Many of the people interviewed highlighted strong family links with the disease, and how many people in their family also suffered from the disease, yet patients still prefer to refer to their condition as an allergy. They also described how common the disease is in Khartoum, and that it was very hard to find someone who was not affected by the disease (despite the stigma surrounding the disease). This is consistent with finding that asthma is the third most common reason for seeking

hospital care in Sudan, and how over-burdened the health care system is with asthma cases (WHO, 2007) .

Family members were reported as key in the decision-making about where to seek asthma treatment. Often the decision was made entirely by the family if the patient was too ill and needed to be treated in an emergency situation. There were also reports of people who trusted a health provider or facility more as they knew of other family members who had been treated there. Word of mouth recommendation was a strong influencing factor in provider choice. Involving patients' families in health promotion activities could be a successful way of improving health education and knowledge about the disease. Further work that delves deeper into this and understands the relative roles different family members play is recommended.

5.2 Individual level factors

5.2.1 Health beliefs affecting choice of provider

In line with the other studies conducted on the knowledge that asthma patients have about their condition, most patients described knowing very little about asthma before their diagnosis except that they believed it was caused by an allergy or is an inherited condition (Merghani et al., 2012; Prasad et al., 2003). The providers also indicated that most of the patients they saw believed allergy and inherited factors were the main causes of their disease. Refusing the diagnosis, and relying on the self-diagnosis of allergy, affected choice of provider and management of the disease

particularly for the younger women interviewed and links with the increased levels of stigma in the community faced by these women. The reluctance to accept the diagnosis due to its long term nature and lack of effective cure was consistent with other studies (Merghani et al., 2012). Providers were sought to treat individual attacks, and so shorter waiting times and availability of treatment (oxygen and nebulisers) were seen as the main criteria for selecting a private facility.

5.2.2 Perceptions of quality of care

In line with other studies, patients perceived a higher quality of care in the private sector (Rannan-Eliya et al., 2015). Habtom and Ruys (2007) found that perceived quality in Eritrea was the most important reason for the choice of a health care provider and that there is a perception of long waiting times, a lack of drugs or personnel and less convenient opening hours in the public sector (Habtom & Ruys, 2007). My findings were consistent with the study described above and found that the public sector was viewed as overcrowded, with long waiting times and sometimes low levels of hygiene. This was a major motivator for seeking care in the private sector. Morgan et al (2016) divide quality of care into two components: service quality (patient satisfaction, responsiveness of staff, waiting times, cleanliness of facilities and longer opening times) and technical quality (adherence to medical standards, prescription guidelines and knowledge of correct diagnosis and treatment) (Morgan et al., 2016). Service quality was viewed by many people interviewed in my sample as much higher in the private sector while the technical quality in the public sector was viewed as higher than in the private sector. The

provider survey was consistent with this, with few private providers following asthma management guidelines.

5.2.3 Health-care-seeking behaviour

The main reason for seeking care was that they were extremely ill. Often the first care-seeking episode was not made by the individual as they were too sick, but by a family member or neighbour. The severity of the disease, and that it often causes death, was a source of great concern for the patients. Many people reported that they knew someone who had died of the disease and that they themselves had gone unconscious from an acute attack. These attacks meant that short-term, fast acting treatment was sought, and so the patients went directly to the hospital emergency room (often repeatedly) for oxygen.

The health providers and the patients reported that people sought asthma care several times a year, and that they would use the hospital emergency room for treatment, especially for acute asthma attacks. In the emergency room, they would access oxygen and nebulisers to relieve the attack. This was consistent with studies in Pakistan and Saudi Arabia (Bilal et al., 2016; Hamdan et al., 2012).

The providers cited a range of reasons for patients to stop treatment, from cost of treatment, the duration between attacks and thus feeling better, worry about long-term inhaler use, and a low understanding of their condition.

5.2.4 Health care utilisation

A strong finding was the frequency with which people sought care for their asthma and that the hospital emergency room was the main place where they sought care. The Global Asthma report (2011) demonstrated that in a pilot project in Gezira, Sudan, there were significant reductions in Emergency room visits when asthma management guidelines were implemented (IUATLD, 2011). The patients interviewed in my study in Khartoum described that if they were acutely ill and needed very urgent care, they would often use a public hospital. If the patient was less ill but still needed prompt treatment, they would often use a private hospital. An acute attack altered choice of provider as the nearest accessible facility was chosen, whether it was private or public. Pharmacies close by were also chosen in preference to those farther away rather than being chosen for quality, reputation or size. Self-referral to upper level health care facilities is often a result of a perception that primary care facilities offer low quality care and a lack of available drugs or personnel (Habtom & Ruys, 2007).

Most patients self-managed their condition and sought care when they felt they needed it. Self-medication was viewed as a low-cost alternative to health care facilities which charged consultation and laboratory fee. This is consistent with other studies, that found the prevalence of self-medication (medicines and herbs) was high in Khartoum (Merghani et al., 2012) (Awad et al., 2006). Those interviewed in this study had no treatment plan or guidance on the steps to take to avoid asthma attacks. They felt they knew what to do to reduce the frequency of the attacks, and

on the whole, avoided going to see doctors for advice. The use of inhalers to treat an attack was accepted but preventer inhalers were used much less often. Pharmacists were the main point of contact for those who were self-medicating, and it is proposed that they have a key role in providing advice to consumers on the safe use of drugs and on inhaler technique (Awad et al., 2006; Osman et al., 2012).

The study participants often used alternative remedies in an attempt to relieve the symptoms during an attack. Other studies found alternative therapies were very frequently used, such as homeopathy and ayurvedic treatments (Prasad et al., 2003). The patients interviewed said that the herbs most used by asthma patients in Khartoum were Nigella seeds (also known as black seed/ kammon) and this was consistent with the findings of one study on self-medication and herb use in Khartoum (Awad et al., 2006). Awad et al (2006) suggested that health education was needed in order to help patients decide on the appropriateness of their alternative remedies.

5.2.6 Health care consequences

Asthma has a major impact on peoples' lives; most people interviewed described how worried and concerned they were for their own wellbeing. They felt they were facing the threat of death, and as a consequence, stopped some activities such as sport or studies. Prasad et al (2003) found similar results; that most people did not feel they could live a normal life and that the disease was often fatal. Some of the older patients in my study were less concerned about their condition and felt that

they were more able to continue to live a fairly normal life. The greatest fears and concerns were felt by younger people with the disease. Merghani et al (2012) also found that people were reluctant to accept the long-term diagnosis of the disease and preferred to consider it as an allergy and so treat the individual attacks rather than look to a sustained management.

5.3 Community and cultural level factors

Communities play a key role in asthma management and shared beliefs often influence health care seeking behaviour. The findings of this study demonstrate how stigma in communities was often very noticeable and resulted in delayed health seeking and case management. This is consistent with other studies that have found that stigma can delay health seeking (Asher & Ellwood, 2014). Stigma was particularly of great concern for the younger women interviewed. The younger asthma patients interviewed in this study reported that people treat them differently when they find out that they are asthmatic. They reported that it can be embarrassing, as people are afraid to argue or create stress as it may trigger an asthma attack. It was reported that patients had met people in the community who feared that asthma is contagious or disgusting. It was felt that it could affect marriage potential, as people do not want to marry someone with a long-term condition. The Global Asthma report (2011) highlighted that the stigma surrounding asthma can affect everyday life including the ability to socialise (IUATLD, 2011). Consistent with the findings described above, the Global report identified that marriage prospects could be affected and the disease was often viewed as

hereditary. Due to inhalers being perceived as addictive, people who use them can be viewed by the community as addicts. As with the individual concerns, these societal concerns were felt more strongly by younger patients in my study and in particular by younger women.

5.4 Organisational and health systems

Strengthening all components of the health system (public and private) is key to overcoming the barriers to effective asthma management and control. Good asthma management requires an uninterrupted supply of high quality, affordable medicines, well trained health professionals, effective diagnostic technologies, asthma guidelines and registers to ensure good information systems and well organized health services (Asher & Ellwood, 2014). This study found that in the private sector in Sudan, many of these essential requirements were lacking, which will be discussed in turn below.

5.4.1 Diagnostic Equipment

The private chest clinics surveyed were better equipped with asthma diagnostic equipment than the private hospitals. The low rates of spirometers and peak flow meters in hospitals (28% and 33%, respectively) found in my study are not unusual, and are comparable with other low income countries (Desalu et al., 2011). The low rates found in the private sector were still higher than in the public sector where there is very little asthma diagnostic equipment available (El Sony et al., 2013). The low rates of equipment were confirmed by the patient interviews which, save for one

individual, described their diagnosis as syndromic. The lack of definitive diagnosis can lead to over/under diagnosis of the condition and rely on the skill of the health provider making the diagnosis.

5.4.2 Asthma registers

Very few of the facilities surveyed used specific asthma treatment registers and relied on the standard Ministry of Health outpatient registers to record asthma patients. The international guidelines recommend the use of standardised asthma registers and the use of asthma treatment cards to assist with asthma management (Ait-Khaled et al., 2006). These were not found in the majority of the private sector facilities surveyed, in Khartoum which makes it difficult for health providers and policy makers to assess the number of people receiving asthma care.

5.4.3 Health Provider training

A key component of the internationally recommended guidelines for asthma management is asthma-specific training for health personnel (Ait-Khaled et al., 2006). Few of the health providers surveyed in my study received asthma-specific training. They all reported that their general training included a component on asthma care, but only one fifth of the hospital doctors surveyed and one third of the doctors at the chest clinics, had undertaken specific asthma training. Asthma is a complicated disease to diagnose, treat and consists of acute attacks and chronic symptoms so specialist training is recommended to ensure patients are given the best support for managing their disease (Beasley, 2011).

5.4.4 Asthma drugs

Asthma drugs were reported by the health facilities surveyed as being stocked, but other studies have found that there are often stock outs when drugs are not available, especially for inhaled preventers (El Sony et al., 2013). Patients highlighted that the availability of drugs was a major issue, particularly in the public sector, and that this was an important motivating factor for accessing services in the private sector. The cost of the drugs was also viewed as a key barrier to managing their disease: both patients and providers cited that cost was the main reason for stopping treatment. Other studies concur that when the public sector has a low availability of drugs, as seen in the public provision of asthma drugs in Khartoum, then the use of the private sector increases (Morgan et al., 2016). A lack of legislated price control has led to a wide variation of prices and was mentioned by many patients as a motivator in where they bought their drugs. Aside from the costs of the drugs, there are other considerable costs such as consultation fees, hospital admissions, complementary treatments (such as blood tests) or indirect costs which other studies have found to be considerable (Nunes et al., 2017).

5.4.5 Asthma Health education

Access to quality of health information regarding health providers and disease specifics has been shown to affect choice of provider (Morgan et al., 2016). The provider survey found that the majority of health providers reported that the asthma health education that was provided to patients focused on counselling. There was a

distinct shortage of asthma leaflets or posters. This lack of health education materials is considerably lower than found by the Nigerian study, where asthma posters or leaflets were available in half of the facilities surveyed (Desalu et al., 2011). The low level of health education materials was highlighted by the patients who reported that they did not have much information about the disease, and by some patients who were not clear on the correct use of inhalers or what the purpose of the different inhalers were. This was consistent with other studies in Sudan and India that found low levels of understanding of the causes of the disease and the associated recommended treatment (Merghani et al., 2012; Prasad et al., 2003). The importance of education in inhaler technique was also highlighted as a key factor affecting patients' treatment (Abdelhamid et al., 2008; Imad & Yasir, 2015). My findings suggest that increasing the role of pharmacists beyond asthma drug dispensing, to patient counselling and education, could act as a way of improving inhaler technique and therefore reduce the occurrence of severe attacks (Abdelhamid et al., 2008; Osman et al., 2012).

5.5 Health Policy

Government commitment to asthma as a priority health condition is highlighted in international guidelines as a key factor for improving health outcomes (IUATLD, 2011, 2018). There is now high level international political support for an increased focus on asthma (Pearce et al., 2013). This support now needs to filter down to country level and lead to countries prioritizing controlling asthma by improving access to essential drugs, technologies and well trained medical personnel. Sudan

does have a National Asthma Strategy but this focuses on the public sector and has only been loosely applied in practice (Asher et al., 2017). This is consistent with other countries, where there has been limited adoption of international guidelines in resource poor settings (Ahmed et al., 2017). Implementing standard case management, strengthening health systems at all levels and using appropriate technologies should be advocated for by the different stakeholders involved in asthma care (Asher & Ellwood, 2014).

5.6 Recommendations:

The main recommendation of this study is that standard asthma case management should be adopted in the private sector in Sudan. As detailed in the Global Asthma report (IUATLD, 2011, 2018), this case management would include:

- legislated price control including reassurances regarding sustained drug availability
- the use of standardised asthma registers and the use of asthma treatment cards
- asthma diagnostic equipment availability
- asthma-specific training for health personnel
- quality asthma health education materials
- patient engagement and education in inhaler technique is a key factor affecting patients' treatment

Adoption of asthma case management has been advocated in many public health settings as a way of increasing access to affordable and sustained asthma services and reduce the need for hospitalisation (Ait-Khaled et al., 2006; Beasley, 2011; El Sony et al., 2013). However, it is not widely advocated for use in the private sector, which as this research shows is a missed opportunity. As so many asthma patients seek care in the private sector, especially on an acute episode by episode basis, there is real potential for asthma case management to be beneficial.

In addition to the points above, the following steps could be taken to improve patient information and help reduce stigma and concern:

- Explore increasing the role of pharmacists beyond asthma drug dispensing, to patient counselling and education

Other studies in the region have found that while pharmacists' skills are currently lacking in asthma advice and guidance (Osman et al., 2012; Van Sickle, 2006), there is the potential to involve them more in asthma counselling. The results of this thesis found that pharmacists were often the first point of contact for asthma patients and their families but focused primarily on the dispensing of inhalers and other associated drugs. Studies have shown that pharmacists can be effective at providing medication counselling and improving inhaler technique (Abdelhamid et al., 2008).

- Explore involving patients' families in health promotion activities as a potential way of improving health education and knowledge about the disease (Adams et al., 2000)

As this result highlights, asthma patients experience high levels of stigma and fear associated with their disease (Andrews et al., 2013; Beasley, 2011; IUATLD, 2018). By strengthening support networks and broadening out health promotion activities to involve patients' families, there is the potential to tackle this fear and provide improved quality of life for asthma patients (Gillen et al., 2014).

- Strengthening all components of the health system (public and private) is key to overcoming the barriers to effective asthma management and control.

Effective asthma management is reliant on a strong and well functioning health system (Ait-Khaled et al., 2001). The overreliance on hospital emergency rooms found in this study and others (Adams et al., 2000) is in part due to asthma services not being freely available at all levels of the health system. Strengthening primary care services and referral systems to manage the disease from acute to chronic stages could be very beneficial for patients and lead to a reduction in life threatening episodes (El Sony et al., 2013).

5.7 Limitations of the study design

While the piloting of the survey and interviews did mean some aspects of the study design could be adapted, the analysis stage of the research highlighted some other weaknesses in the methodology. These centred around the sampling of health personnel and the sampling of the asthma patients.

The selection of health workers in the facilities was open to bias and this was much more apparent for the hospitals. The study lacked a clear sampling frame of age,

gender, profession (doctor/ nurse) and where these workers interacted most with asthma patients (emergency room, outpatient department). Most of the surveys were conducted with Emergency Room health workers but this should have been complimented with some surveys conducted with outpatient health workers to look for contrasts and similarities. There was also a reliance on the English survey format. An Arabic and English version of the questionnaire should have been offered to each participant so that they could answer the version they meant most comfortable with. Another key weakness of the survey was that often the providers were being asked to estimate numbers of patients, numbers of diagnostic devices and availability of drugs. Checking the hospital records to validate the answers the providers gave could have given a good insight into their level of knowledge and reality of the services available at their facility. The timing of the fieldwork was at a time of security uncertainty with widespread protests by certain occupations including doctors and other health professionals. This meant that getting permissions from health facilities to conduct the research and to get people to respond to the survey was more difficult than usual. It was not possible to delay the research as it was unclear how long the unrest would continue for. Those health professionals that did kindly participate gave their time willingly but I was very aware that their jobs were at increased stressed and so I wanted to minimise the impact this research project had on them.

A key limitation of the qualitative interviews was the reliance of health providers acting as gate keepers to recommend patients for interview. This may have meant

that the selection of people was narrower than a standard representative sample of asthma service users. Initially, the sampling framework set out that four people would be identified per facility type. However, this was not realistic as people used several facility types (hospital, clinic, pharmacy) and so were not able to restrict their responses to one facility use. A weakness however, was not to record which gatekeeper (from which facility) recommended them and to see whether this affected their responses.

Another option could have been to have identified patients from the hospital registers but these registers were often not well completed and so it would have been difficult to get patients' home contact information. It was also thought that a direct approach by the research team in this way could have been in breach of the confidential nature of the records.

A limitation of using a data collection team was that whilst there were clear advantages for using local interviewers for this work, there were also disadvantages in that because the interviewers were sticking closely to the interview schedule, on occasions, they or I were unable to follow up on interesting but unanticipated issues arising from the interview.

5.8 Reflections on data quality

The health workers were asked a combination of closed fixed answer questions and open-ended questions. However, this latter type of question was not recorded well using the electronic questionnaire (ODK) format. It would have been better to have

recorded the surveys and then transcribed the answers. This would have given the opportunity to code the responses and capture the depth more effectively.

The interviews were reliant on the interview skill of the interviewer in encouraging and probing the participants. While conducting the interviews in Arabic meant for a more natural conversation between the interviewer and interviewee, it did mean that I was not able to participate as fully as I would have liked and there were areas that I would have explored/ probed more if I had fluent Arabic.

There was a lack of socioeconomic details collected from the patients interviewed. This was purposively avoided so that rapport could be built more easily but should have been asked at the end of the interview. This meant that it was not possible to code according to socioeconomic status or income level. This limited the possibility of ascertaining whether different socioeconomic groups preferred different types of private provider and whether their income status affected their rationale for selecting one provider over another.

Another limitation was that understanding that the study did not have a component that interviewed community members or family members directly but relied on the patients' accounts of their reactions. This meant that there was an element of bias as the patient may not accurately report the opinions of others and could over (or under) emphasis the stigma felt from others around them.

5.9 Areas for future research

While there have been quantitative studies with public health providers, there has been little qualitative work regarding patients that solely use the public sector in Sudan. In Sudan, the pluralistic health system means that most people use a variety of public and private sectors (as opposed to exclusively one or the other), this may not be the case in other countries and so could be explored further in future studies as comparison to these findings.

A key area for future research is around the health economic barriers of asthma care; the cost and affordability of inhalers, the financial implications of having the disease on lack of productivity (patient costs) and the effectiveness of insurance for asthma care.

5.91 Contribution to knowledge

There are no other studies that have investigated which asthma services exist in the private health sector in Sudan, and what motivates people to seek care in the private sector.

The health care seeking of asthma patients was shown to be a complex combination of need, social forces, and access issues, in line with studies on choice of provider for other health conditions in developing countries (Hausmann-Muela, Ribera, & Nyamongo, 2003) . Of these factors, social forces were very affected by the age of the patient; younger people were more concerned about severity, impact of their lives, and how their condition affects their social interaction with others. There were

Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in 163

few gender differences regarding severity between young asthma patients with both groups describing the huge impact the disease has on their life and how it affects their activities and plans for the future. However, there were gender differences surrounding stigma, with younger women reporting the highest levels of stigma from their community as a result of having the disease. Older males tended to be more confident when describing their disease and felt that it limited their activities less than other groups.

The Social Ecological approach has been helpful in understanding the multiple levels of influence of the health-care-seeking-behaviour of asthma patients in Khartoum and how the different levels interact (Peters et al., 2008; Shahabuddin et al., 2017). Factors from the organisational and health system level (availability of drugs, diagnostics, location and treatment services – oxygen, nebulisers) interacted with individual level factors, such as the patient’s health beliefs and willingness to pay and with the societal and familial factors such as stigma and social norms. The interaction between the levels and how some issues cross levels is important to understanding the multiplicity of decision-making and provider choice for asthma care. Familial/interpersonal influence and community perceptions of the disease and of the quality of facilities can have a major influence on an individual’s health seeking behaviour. Issues such as severity and refusal to accept the long-term nature of asthma meant patients sought short-term care for acute attacks and cross different levels of influence. A lack of health policy prioritising asthma care in the public sector, a lack

of regulation in the private sector and the barriers described above, impact on care seeking and ultimately on health outcomes.

6. Conclusion

By using a Social Ecological approach, this thesis has offered an understanding of the different levels that influence asthma service delivery in the private sector, and how and why asthma patients utilise these services. The phased mixed-method approach gathered different data that complemented each other to provide a fuller understanding of if, where, why and how asthma patients seek care (Greene, 2008).

Studies that model supply and demand factors have argued that greater access to quality services can lead to more effective treatment of a disease (Grundy & Annear, 2010; Peters et al., 2008). However, the findings described above in this study in Khartoum highlight that choice of provider and management of disease is more than supply and demand; decision-making involves multiple levels of influence and different perspectives that incorporate severity and health care consequences and these factors all interact to affect health outcomes.

Adopting a Social Ecological approach to examine asthma health seeking and provider choice has facilitated the understanding regarding which factors influence decision-making by asthma patients in Khartoum. This study provides evidence that decisions regarding asthma treatment are influenced by age, severity of disease and perceived quality of services.

A key part of successful asthma management requires patients to be empowered so that they have a good understanding of their condition, a willingness to accept the

diagnosis, a supportive social environment and thus they are able to treat the condition between attacks. Health care choices in Khartoum are currently made on an attack-by-attack basis and short-term acute care is sought rather than long term management of the disease. The private sector, while viewed as expensive, is also viewed to have a higher quality of care and one where the treatment will be delivered faster, which is vital in the case of an acute attack.

Organisational and health system issues such as a lack of available and affordable drugs need to be addressed alongside increasing demand for services and perceived quality of care received by different providers. Asthma programmes need to promote the benefits of long-term management of the condition and how it will reduce the frequency and severity of the attacks, reducing hospital admissions and should lead to individuals living a more normal life. Implementing the International Guidelines for Asthma Care in Khartoum in the private sector would be very beneficial as the Guidelines address the different levels from Political commitment to drug availability, training and diagnostics. Pilot studies in Sudan have shown implementing standard case management systems in the public sector can be very beneficial and recommended rolling these systems out more extensively (El Sony et al., 2013). Encouraging private sector providers to implement standard case management should lead to a reduction in emergency room admissions, less severe attacks, and reduced asthma related fear and concern for the patients.

This study took a patient- centred approach so that asthma patients' perception of their disease would be highlighted and their preferences for care seen as crucial to planning of any improvements to service delivery. The reasons behind patients' choice of health care need to be addressed alongside provision of appropriate services to reach improve outcomes for asthma patients. Targeting all the layers of influence on health seeking and provider choice is the most likely to create sustainable health improvements.

Annex A: Summary of Reviewed journal articles

Access								
					location	Design	Aim/research question	Key finding
1	Andaleeb, S. S	Service quality perceptions and patient satisfaction: a study of hospitals in a developing country.	Soc Sci Med, 52(9), 1359-1370.	2001	Bangladesh	Patient survey	To identify service quality factors important to patients	Significant association between service quality (communication, responsiveness) and patient satisfaction
2	Awad, A., Eltayeb, I., Matowe, L., & Thalib, L.	Self-medication with antibiotics and antimalarials in the community of Khartoum State, Sudan	J Pharm Pharm Sci, 8(2), 326-331.	2005	Sudan	Household questionnaire	To estimate self-medication	Highly associated with age, income, gender, high levels of self-medication found.
3	Awad, A. I., Eltayeb, I. B., & Capps, P. A.	Self-medication practices in Khartoum state, Sudan.	European journal of clinical pharmacology, 62(4), 317-324.	2006	Sudan	Household survey	To estimate the prevalence of self-medication with proprietary medicines and herbs in Khartoum State, Sudan, and to	The prevalence of self-medication with medicines including herbs in urban areas of Khartoum State is high. Self-medication behaviour varies significantly with a number of socio-economic characteristics

							evaluate factors associated with self-medication.	
4	Kamel, M., Rashed, S., Foda, N., Mohie, A., & Loutfy, M.	Gender differences in health care utilization and outcome of respiratory tuberculosis in Alexandria.	East Mediterr Health J, 9(4), 741-756.	2003	Egypt	Patient cohort	To understand gender differences in TB	Women had lower knowledge levels of the disease but started treatment earlier. No difference in treatment outcome.
5	Lule, F., & Allwright, S	Health-seeking behaviour for common illnesses in a low-income population in Kampala, Uganda	The new public/private mix in health: exploring the changing landscape, 136	2003	Uganda	Household survey	To understand perceptions of public/ private services	Good quality care in public sector, costs very similar.
Asthma								
6	Abdelhamid, E., Awad, A., & Gismallah, A.	Evaluation of a hospital pharmacy-based pharmaceutical care services for asthma patients.	Pharmacy Practice (Internet), 6(1), 25-32.	2008).	Sudan	Random control trial in teaching hospital	To compare pharmacists and physicians in the quality of their prescribing.	Positive impact on patients' asthma when prescribed inhalers by pharmacists
7	Bilal, M.,	Factors associated with patient visits	Asia Pacific family	2016	Pakistan	Patient survey	To assess reasons for use of	Irregular clinic follow ups, education level, low

	Haseeb, A., Khan, M. H., Saad, M., Devi, S., Arshad, M. H., . . . Javed, K. M. A. A	to the emergency department for asthma therapy in Pakistan	medicine, 15(1), 1.				emergency department by asthmatic patients	knowledge of the disease lead to increased visits to the ED
8	Bosnic-Anticevich, S. Z., Stuart, M., Mackson, J., Cvetkovski, B., Sainsbury, E., Armour, C., . . . Williamson, M.	Development and evaluation of an innovative model of inter-professional education focused on asthma medication use.	BMC Med Educ, 14, 72. doi:10.1186/1472-6920-14-72	2014	Australia	Mixed methods: different styles of professional education tested	To develop and evaluate professional education to engage patients and improve inhaler use	Significant financial and time resources needed to make an impact in education for inhaler use

9	Desalu, O. O., Onyedum, C. C., Iseh, K. R., Salawu, F. K., & Salami, A. K.	Asthma in Nigeria: Are the facilities and resources available to support internationally endorsed standards of care?	Health Policy, 99(3), 250-254.	2011	Nigeria	Hospital based cross sectional survey	to assess the facilities and resources available to support internationally endorsed standards of asthma care at tertiary hospitals	The available facilities and human resources for asthma management in Nigerian tertiary hospitals were not enough to support the standard internationally endorsed for asthma care.
10	El Sony, A., Chiang, C., Malik, E., Hassana in, S., Hussien, H., Khamis, A., . . . Enarson, D.	Standard case management of asthma in Sudan: a pilot project.	Public Health Action, 3(3), 247-252.	2013	Sudan	Pilot hospital based project – longitudinal study	To assess the implementation of standard case management in two states in Sudan	The results of standard case management of asthma were encouraging; however, a high proportion of patients did not return for long-term management
11	Elamin, S., Mergha	Adequacy of asthma management among patients	Khartoum Medical Journal, 4(1).	2012	Sudan			

	ni, T., & Alawad, A.	attending referred clinics in Khartoum.						
12	Hamdan, A.-J., Anwar, A., Abdullah, A.-H., Baharon, S., Halwani, R., Al Shimemeri, A., & Al-Muhsen, S.	Factors associated with patient visits to the emergency department for asthma therapy	BMC pulmonary medicine, 12(1), 1.	2012	Saudi Arabia	Patient cross sectional survey	To review factors for the frequent admission of asthmatic patients to the ED	Highly related to reduced inhaler use, little knowledge about the disease
13	Imad, H., & Yasir, G	Epidemiological and clinical characteristics, spirometric parameters and response to budesonide/formoterol in patients attending an asthma clinic: an	The Pan African Medical Journal, 21.	2015	Sudan	Retrospective patient chart review	To look at the asthma characteristics using spirometry	Spirometry was helpful in identifying severe asthma and when it had improved after inhaler use

		experience in a developing country.						
14	Koshak, A., Wei, L., Koshak, E., Wali, S., Alamoudi, O., Demerdash, A., ... Heinrich, M.	Nigella sativa Supplementation Improves Asthma Control and Biomarkers: A Randomized, Double-Blind, Placebo-Controlled Trial.	Phytother Res, 31(3), 403-409. doi:10.1002/pt.r.5761	2017	Saudi Arabia	Random controlled trial	To investigate the benefits of Nigella seed on asthma outcomes	Nigella seeds were found to improve lung function
15	Merghani, T. H., Zaki, A. M., Ahmed, A. M., & Toum, I. M.	Knowledge, attitude and behaviour of asthmatic patients regarding asthma in urban areas in Khartoum State, Sudan.	Khartoum Medical Journal, 4(1).	2012	Sudan	Patient questionnaire	To evaluate the knowledge and beliefs of asthmatic patients about asthma and to assess their attitude and behaviour	Asthmatic patients in Khartoum State have poor knowledge about the pathogenesis of asthma, especially the inflammatory nature of the disease. More than a quarter of them are reluctant to accept the diagnosis of asthma and prefer to be described as allergic.
16	Schultz, C.	An audit of the management of	Primary Care Respiratory	2002	Yemen	Hospital audit	Audit use of liquid salbutamol/ audit	

		asthma in an urban health centre in Yemen.	Journal, 11, 52-53.				management of asthma	Lack of inhalers available, cultural barriers of patients, lack of education of health care professionals all contribute to low inhaler prescription and use.
17	Van Sickle, D.	Management of asthma at private pharmacies in India	The International Journal of Tuberculosis and Lung Disease, 10(12), 1386-1392.	2006	India	Simulated client study	To examine the medications and advice that retail pharmacy attendants recommend to customers presenting with typical symptoms of asthma in an urban area of India	The majority of individuals presenting with asthma symptoms did not receive appropriate advice or medications from pharmacy attendants.
PRIVATE								
18	George, D. A., Shah, I., & Nandraj, S.	Household health expenditure in two states: a comparative study of districts in Maharashtra and Madhya Pradesh:	Foundation for Research in Community Health Pune/Mumbai.	1997	India	Household survey	To examine the costs of households using private and public facilities	Most people preferred the private sector and all socioeconomics cadres used it. No significant costs involved between the two sectors.

19	Ha, N. T. H., Berman, P., & Larsen, U.	Household utilization and expenditure on private and public health services in Vietnam	Health Policy and Planning, 17(1), 61-70.	2002	Vietnam	Household survey	To assess the role of the private health care provider by examining utilization patterns and financial burden for households of private, as compared with public, services.	There was no difference by education, sex or place of residence in the use of private ambulatory health care. Although there was evidence suggesting that rich people use private care more than the poor, this finding was not consistent across all groups.
20	Kamat, V. R., & Nichter, M.	Pharmacies, self-medication and pharmaceutical marketing in Bombay, India	Social science & medicine, 47(6), 779-794.	1998	India	Ethnographic study	To the context in which pharmacy attendants engage in "prescribing medicines" to the public	The economic rationale and the symbiotic relations that exist between doctors, medreps, medicine wholesalers and retailers, need to be more closely scrutinized by those advocating "rational drug use".
21	Osman, A., Hassan, I. S. A., & Ibrahim, M. I. M.	Are Sudanese community pharmacists capable to prescribe and demonstrate asthma inhaler devices to patrons?	Pharmacy practice, 10(2), 110-115.	2012	Sudan	Mystery patient study	To evaluate community pharmacists' practical knowledge and skills of demonstrating proper inhalation technique of asthma	The majority of community pharmacists, who were expected to educate asthma patients on their dispensed inhalers, lack the basic knowledge of proper use of commonly dispensed asthma inhaler devices

		A mystery patient study.					inhaler devices available in Sudan	
22	Rannan-Eliya, R. P., Wijemanne, N., Liyanage, I. K., Jayanthan, J., Dalpata du, S., Amarasinghe, S., & Anuranga, C.	The quality of outpatient primary care in public and private sectors in Sri Lanka—how well do patient perceptions match reality and what are the implications?	Health Policy Plan, 30(suppl 1), i59-i74.	2015	Sri Lanka	Retrospective cross sectional hospital comparison record survey	To compare the quality of inpatient clinical care in public and private hospitals in Sri Lanka	Quality in the public sector is better than in the private sector in many areas, despite spending being substantially less
23	Russell, S.	Treatment-seeking behaviour in urban Sri Lanka: trusting the state, trusting private providers.	Social science & medicine, 61(7), 1396-1407.	2005	Sri Lanka	Household survey data and qualitative data show that people from a range of	Effect of patient trust on treatment-seeking behaviour and the treatment costs incurred by poor households	Poor relationships act as an access barrier and push a range of income groups to the private sector

						income groups		
	Respiratory							
24	Ahmed, R., Robinson, R., Elsony, A., Thomson, R., Squire, S. B., Malmbo rg, R., . . . Mortimer, K.	A comparison of smartphone and paper data-collection tools in the Burden of Obstructive Lung Disease (BOLD) study in Gezira state, Sudan.	PLoS One, 13(3), e0193917. doi:10.1371/journal.pone.0193917	2018	Sudan	Cross sectional household survey	To compare smartphone and paper based data collection systems in the Bold Lung disease study	Compared to paper-based data collection, smartphone technology worked well for data collection in the study, which was conducted in a challenging rural environment in Sudan. This approach provided timely, quality data with fewer errors and inconsistencies compared to paper-based data collection

Annex B:

List of facilities surveyed

	Hospitals	Clinics	Pharmacies
1	El-ateiba hospital	Mahmoud abd almotaal Omer	Gaser 3
2	Faisal hospital	Iman slieb tobia	Alawl-khartoum2
3	Dar el-fouad specialized hospital	Haider abdalla abd alslam	Aghadeer
4	Aljawdah hospital	Marwan abd almalik bashier	Alawl- khartoum 2
5	Imperial hospital	Alaa aldien hassan ahmed	Alawl Khartoum 2
6	Shawameikh	Gatar elnada abd alla	Taieba
7	Royal care	Mawahib farah	Albroj
8	El-amal hospital	Alfatih al bashier mohamed ahmed	Elhmad
9	Elsharif specialist hospital	Afaf ageed mohamed	Anwr Alalmia
10	El-tabib Elmarkazi Hospital		Alzohor
11	Heraa Hospital		Shafaq shares Mohamed najeb
12	Jarash international specialist hospital		Aliaa alsahafa shariq
13	El-SAFA HOSPITAL		Alinjaz
14	Best care		Noon
15	El-shefaa hospital		Elgameia eltibia elislamia 3
16	El-sheikh professional hospital		Alomri
17	Delmon Hospital		Aghadeer
18	Yastabshroun hospital		Gaser 3
19	Fedail hospital		Alsafwa
20	Dar El-Elaj hospital		Elrowad
21	Alzaytouna specialist hospital		Sun way
22			Ashmeg khalifa
23			Ozone
24			Hamdi Abo haraz
25			Alrayah
26			Sidrat elmontaha
27			Alisaaf
28			Alfarabi
29			Rabaa eladawia

30			Bate elshifaa
31			Alikhlas 2
32			Merna
33			Alamasi
34			Alsawahi
35			Jood
36			Future
37			Pioneer alriyad
38			Kambal algadded
39			Aloum - Sudan
40			Beat alhamad
41			Aliaa - alsaidala alitihadia
42			Makkah 5
43			Abo ahmed
44			Senin

Annex C:

**Ethics approval letters from the Liverpool School of Tropical Medicine and
Khartoum Ministry of Health**

Rachael Thomson
Liverpool School of Tropical Medicine
Pembroke Place
Liverpool
L3 5QA

Wednesday, 08 January 2014

Dear Ms Thomson,

Re. Research Protocol (13.33) Understanding the role of private providers in adult asthma treatment in Khartoum

Thank you for your correspondence of the 08/01/2014 providing the necessary in-country ethical approval documents required for this study. The protocol now has formal ethical approval from the Chair of LSTM Research Ethics Committee.

The approval is for a fixed period of three years and will therefore expire on 07/01/2017. The committee may suspend or withdraw ethical approval at any time if appropriate.

Approval is conditional upon:

- Continued adherence to all in-country ethical requirements.
- Notification of all amendments to the protocol for approval before implementation.
- Notification of when the project actually starts.
- Provision of an annual update to the Committee. Failure to do so could result in suspension of the study without further notice.
- Reporting of new information relevant to patient safety to the Committee
- Provision of Data Monitoring Committee reports (if applicable) to the Committee

Failure to comply with these requirements is a breach of the LSTM Research Code of Conduct and will result in withdrawal of approval and may lead to disciplinary action. The Committee would also like to receive copies of the final report once the study is completed.

Please quote your Ethics Reference number with all correspondence.

Yours sincerely



Dr Angela Obasi,
Chair,
LSTM Research Ethics Committee

Republic of Sudan
National Ministry of Health

HEALTH RESEARCH COUNCIL

NATIONAL RESEARCH ETHICS REVIEW COMMITTEE

Date: 7/1/2014

Provisional Ethical Clearance Certificate

This is to certify that the proposal entitled (understanding the role of private providers in adult asthma treatment in Khartoum) submitted by: Mrs. Rachael Thomson, from Epidemiological Laboratory(Epi-Lab), has been approved by the National Health Research Ethics Committee, Federal Ministry of Health to be carried out in the Sudan.

NB

The final ethics clearance certificate will be granted after submission of the final report to the Research Directorate- Federal Ministry of Health.

7/1/2014

Dr. Inan Abdalla Mustafa
Reporter of the
National Research Ethics Review Committee

Annex D: questionnaires

ASTHMA Private Hospitals survey

note to interviewer: have you given the respondent the information sheet and explained a little about the project?

note to interviewer: has the respondent signed the consent form?

Enter today's date:

.....

1.0 General Information

1.1 Health facility name

.....

1.2 Health facility type

- Specialist Hospital
- General Hospital

1.3 Health facility size

- Large
- Medium
- Small

1.4 Name of person surveyed (optional)

.....

1.5 Are you

- Male
- Female

1.6 Role of person surveyed

- Chest Physician
- General Doctor
- Nurse
- Administrator

1.7 In which age group are you? (optional)

- 0 – 16
- 17 – 29
- 30 – 45
- 46 – 60
- 60+

2.0 Asthma services offered and availability of basic infrastructure

2.1 What type of asthma treatment services are available?

- Clinic
- Diagnosis
- Drugs
- Clinical Assessment
- Prevention
- Health Education

2.2 Do you have asthma registers?

- Yes
- No

2.3 Do you have asthma protocols/guidelines?

- Yes
- No

2.4 Where were the protocol/guidelines developed?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.5 Have any of your staff had specific asthma training?

- Yes

- No

2.6 If so, how many people have had training please estimate?

.....

2.7 What was the training?

.....

2.8 When was it carried out?

.....

2.9 Where was it carried out?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.91 Number of asthma patients please estimate?

.....

2.92 How many asthma patients do you see per month?

.....

2.93 How many are one off visits?

.....

2.94 How many are repeat visits?

.....

2.95 How many times would the same individual visit a year please estimate?

.....

2.96 Please estimate if you see more children, more adults, or the same of each?

- More Children
- More Adults
- Same of Each

2.97 Please estimate if you see more males, more females, or the same of each?

- More Females
- More Males
- Same of Each

2.98 Most common type of asthma treated at your centre

- Intermittent
- Mild persistent
- Moderate persistent
- Severe persistent

3.0 Availability of equipment

3.1 Do you have a spirometer at this hospital?

- Yes
- No

If yes, how many?

3.2 Do you have a peak flow meter at this hospital?

- Yes
- No

If yes, how many?

4.0 Availability and type of asthma drugs

4.1 Do you stock asthma drugs?

- Yes
- No

5.0 Facilities for health education and support

5.1 Does your centre offer any health education services?

- Yes
- No

5.2 If yes, do you have any specific asthma health education?

- Yes
- No

5.3 If yes, what sort of health education do you offer?

- Leaflets
- Counselling
- discussion groups
- posters

5.4 If yes, how often does this take place?

.....

5.5 If yes, who provides the services?

.....

6.0 Health provider's view of the pathway to care
--

6.1 In your opinion, what was the first point of care-seeking by the patient?

.....

6.2 In your opinion what is the patient's level of knowledge/ understanding of their asthma diagnosis?

.....

6.3 What treatment do you prescribe for mild persistent asthma?

.....

6.4 Do some patients stop their treatment?

.....

6.5 What do you think the reasons for this are?

.....

6.6 Do most patients comply with their treatment?

- Yes
- No

If not, why not?

6.7 Are the patient's visits usually urgent, non urgent, same other?

- Urgent
- Non Urgent
- Same

Thank you for your time, we really appreciate your help in completing this survey.

ASTHMA Private Clinic survey

note to interviewer: have you given the respondent the information sheet and explained a little about the project?

note to interviewer: has the respondent signed the consent form?

Enter today's date:

.....

1. General Information

1.1 Health facility name

.....

1.2 Health facility type

- Specialist Clinic
- General Clinic

1.3 Health facility size

- Large
- Medium
- Small

1.4 Name of person surveyed (optional)

.....

1.5 Are you

- Male
- Female

1.6 Role of person surveyed

- Chest Physician
- General Doctor

- Nurse
- Administrator

1.7 In which age group are you? (optional)

- 0 – 16
- 17 – 29
- 30 – 45
- 46 – 60
- 60+

Opening hours of the centre

1.8 What time does the centre open?

.....

1.9 What time does the centre close?

.....

1.91 Number of staff working at the centre?

.....

2.0 Asthma services offered and availability of basic infrastructure

2.1 What type of asthma treatment services are available?

- Clinic
- Diagnosis
- Drugs
- Clinical Assessment
- Prevention
- Health Education

2.2 Do you have asthma registers?

- Yes
- No

2.3 Do you have asthma protocols/guidelines?

- Yes
- No

2.4 Where were the protocol/guidelines developed?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.5 Have any of your staff had specific asthma training?

- Yes
- No

2.6 If so, how many people have had training please estimate?

.....

2.7 What was the training?

.....

2.8 When was it carried out?

.....

2.9 Where was it carried out?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.91 Number of asthma patients please estimate

.....

2.92 How many asthma patients do you see per month?

.....

2.93 How many are one off visits?

.....

2.94 How many are repeat visits?

.....

2.95 How many times would the same individual visit a year please estimate?

.....

2.96 Please estimate if you see more children, more adults, or the same of each

- More Children
- More Adults
- Same of Each

2.97 Please estimate if you see more males, more females, or the same of each

- More Females
- More Males
- Same of Each

2.98 Most common type of asthma treated at your centre

- Intermittent
- Mild persistent
- Moderate persistent
- Severe persistent

3.0 Availability of equipment

3.1 Do you have a spirometer at this centre?

- Yes
- No

If yes, how many?

3.2 Do you have a peak flow meter at this centre?

- Yes
- No

If yes, how many?

4.0 Availability and type of asthma drugs

4.1 Do you stock asthma drugs?

- Yes
- No

5.0 Facilities for health education and support

5.1 Does your centre offer any health education services?

- Yes
- No

5.2 If yes, do you have any specific asthma health education?

- Yes
- No

5.3 If yes, what sort of health education do you offer?

- Leaflets
- Counselling
- discussion groups
- posters

5.4 If yes, how often does this take place?

.....

5.5 If yes, who provides the services?

.....

6.0 Health provider's view of the pathway to care

6. 1 In your opinion, what was the first point of care-seeking by the patient?

.....

6.2 In your opinion what is the patient's level of knowledge/
understanding of their asthma diagnosis?

.....

6.3 what treatment do you prescribe for mild persistent asthma?

.....

6.4 do some patients stop their treatment?

.....

6.5 what do you think the reasons for this are?

.....

6.6 do most patients comply with their treatment?

- Yes
- No

If not, why not?

6.7 Are the patient's visits usually urgent, non urgent, same other?

- Urgent
- Non Urgent
- Same

Thank you for your time, we really appreciate your help in
completing this survey.

ASTHMA Private Pharmacy survey

note to interviewer: have you given the respondent the information sheet and explained a little about the project?

note to interviewer: has the respondent signed the consent form?

Enter today's date:

.....

2. General Information

1.1 Health facility name

.....

1.2 Health facility type

- Single Pharmacy
- Part of a chain

1.3 Health facility size

- Large
- Medium
- Small

1.4 Name of person surveyed (optional)

.....

1.5 Are you

- Male
- Female

1.6 Role of person surveyed

- Pharmacist

- Administrator
- Assistant

1.7 In which age group are you? (optional)

- 0 – 16
- 17 – 29
- 30 – 45
- 46 – 60
- 60+

Opening hours of the pharmacy

1.8 What time does the pharmacy open?

.....

1.9 What time does the pharmacy close?

.....

1.91 Number of staff working at the pharmacy?

.....

1.92 How many days of the week are asthma services provided?

.....

2.0 Asthma services offered and availability of basic infrastructure

2.1 What type of asthma treatment services are available?

- Clinic
- Diagnosis
- Drugs
- Clinical Assessment
- Prevention
- Health Education

2.2 Do you have asthma registers?

- Yes
- No

2.3 Do you have asthma protocols/guidelines?

- Yes
- No

2.4 Where were the protocol/guidelines developed?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.5 Have any of your staff had specific asthma training?

- Yes
- No

2.6 If so, how many people have had training please estimate?

.....

2.7 What was the training?

.....

2.8 When was it carried out?

.....

2.9 Where was it carried out?

- At this centre
- At the ministry of health
- At another private provider
- At another organisation

2.91 Number of asthma patients please estimate

.....

2.92 How many asthma patients do you see per month?

.....

2.93 How many are one off visits?

.....

2.94 How many are repeat visits?

.....

2.95 How many times would the same individual visit a year please

estimate

.....

2.96 Please estimate if you see more children, more adults, or the same

of each

- More Children
- More Adults
- Same of Each

2.97 Please estimate if you see more males, more females, or the same

of each

- More Females
- More Males
- Same of Each

2.98 Most common type of asthma treated at your centre

- Intermittent
- Mild persistent
- Moderate persistent
- Severe persistent

3.0 Availability of equipment

3.1 Do you have a spirometer at this centre?

- Yes
- No

If yes, how many?

3.2 Do you have a peak flow meter at this centre?

- Yes
- No

If yes, how many?

4.0 Availability and type of asthma drugs
--

4.1 Do you stock asthma drugs?

- Yes
- No

4.2 Which type of drugs do you have available?

- Anti-inflammatory
- Bronchodilator
- Beclomethasone
- Salbutamol
- Budesonide

4.3 What is the cost of anti-inflammatory stocked?

.....

4.4 What is the cost of bronchodilator stocked?

.....

4.5 What is the cost of beclomethasone stocked?

.....

4.6 What is the cost of salbutamol stocked?

.....

4.7 What is the cost of budesonide stocked?

.....

4.8 What is the average number of asthma drug units sold per month at your centre?

.....

4.9 Where do you procure your asthma drugs from?

.....

5.0 Facilities for health education and support

5.1 Does your centre offer any health education services?

- Yes
- No

5.2 If yes, do you have any specific asthma health education?

- Yes
- No

5.3 If yes, what sort of health education do you offer?

- Leaflets
- Counselling
- discussion groups
- posters

5.4 If yes, how often does this take place?

.....

5.5 If yes, who provides the services?

.....

6.0 Health provider's view of the pathway to care

6. 1 In your opinion, what was the first point of care-seeking by the patient?

.....

6.2 In your opinion what is the patient's level of knowledge/ understanding of their asthma diagnosis?

.....

6.3 What treatment do you prescribe for mild persistent asthma?

.....

6.4 Do some patients stop their treatment?

.....

6.5 What do you think the reasons for this are?

.....

6.6 Do most patients comply with their treatment?

- Yes
- No

If not, why not?

6.7 Are the patient's visits usually urgent, non urgent, same other?

- Urgent
- Non Urgent
- Same

6.8 Do patients have insurance that pays for their asthma treatment?

- quite a lot
- half and half
- only a few
- very few
- none

Thank you for your time, we really appreciate your help in completing this survey.

Annex E: Topic Guide: In-depth interviews – patients

All the interviews will cover the 5 main topic areas:

- **Access:** awareness of services, location, price,
- **Utilisation:** rate and pattern of use of services
- **Demand for service:** health behaviour, reason for seeking health care
- **Perceptions of quality of care:** as a motivator or barrier to service utilisation
- **Health beliefs:** traditional belief systems, shared misconceptions

Objectives:

1. Barriers and facilitators of asthma diagnosis and treatment in public and private facilities
2. Community knowledge and perceptions about asthma

Step 1: Introduction of yourself (see informed consent form if you are seeking consent immediately before IDI)

Step 2: Introduction to the interviews and its purpose and the project

Step 3: Obtain consent (if not previously sought) and permission to record the interview

Step 2: In Research Diary:

- Record sex: M/F
- Place and date of interview
- Type of interviewee
- Other observations about interviewee, body language, demeanour etc.

General Questions

1. Please tell me a bit about yourself. *Probe about the age, family, marital status, children, language, how long have you stayed in this area? Where were you born?*

Access: awareness of services, location, price

2. We would like to know more about your experience in being diagnosis with asthma (and treatment – if applicable). Please describe what has happened

Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in 203

from the time you first felt sick (with wheeze etc.) until you received diagnosis at the health centre (the aim is to receive a chronological story of the events).

3. Please describe the process of the diagnosis/treatment? *How did the topic of asthma come up? How do you suspect you have asthma? Probe: through friend/relative / Noticed coughing*

Utilisation: rate and pattern of use of services

4. What do you think about the asthma centres in your area? *Probe about the services*
5. What do you think about the service at the public health centre?
6. Did you seek any treatment before coming here? *Probe: Please tell me about it; from where/whom before you were referred did you get any medicine from any other healer??*
7. After you received your result how were your subsequent visits to the health centre? *Probe did they make follow up appointments?*
8. Did they ask you to pay for any of the services and follow-up at the hospital?

Demand for service: health behaviour, reason for seeking health care

9. What do you know about asthma? *Where did you get this information about TB?*
10. Do you know anybody with asthma? *What do you know about their experience?*
11. Does your community sometimes talk about asthma? *Probe How does this community think/feel about discussing asthma issues? Do you have suggestions on how you would increase awareness about asthma?*
12. What do you think people in this community know about asthma treatment? *Probe about cost of treatment, where to get treatment? Do people think you can be cured? Etc.*
13. What would encourage people to seek asthma treatment?
14. Is asthma a concern to you?

Perceptions of quality of care: as a motivator or barrier to service utilisation

15. What are your views on the quality of asthma care in the public sector and why?
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16. What are your views on the quality of asthma care in the private sector?

17. What can be done differently for the benefits of the patients and how?

Health beliefs: traditional belief systems, shared misconceptions

18. How did you feel when you received your asthma diagnosis?

19. Did you tell anyone that you were referred for asthma diagnosis? Probe, if no, why not? If yes, how did they react? How did you feel when you told them?

20. (When diagnosed with asthma:) After you discovered you have asthma did you tell people that you have asthma? *Probe: How did the family and community respond to you? Are they supportive?*

At the end of the interview thank the respondent for the valuable information; ask them if they have any questions or anything more to add.

After the interview write more observations to the research diary, and things that will help you remember a specific respondent (this is helpful during the analysis, so you can visualize the respondent).

Annex F: Informed consent forms and participant information sheets

	<p>“Understanding the role of private providers in adult asthma treatment in Khartoum”</p> <p>INFORMED CONSENT</p>
	<p><i>Information given to participants:</i></p>
<p style="text-align: center;">Informed Consent Form for Enrolment to In Depth Interview (IDI)</p> <p>STUDY PARTNERS</p> <p>EPILAB Khartoum, Liverpool School of Tropical Medicine (LSTM) and Lancaster University</p> <p>INTRODUCTION</p> <p>This consent form tells you about the research study that aims to understand and document the choices made about asthma treatment by patients, and assess the potential impact of different providers of that treatment. To be sure that you are well informed about your rights and what is being requested of you in this research, we are asking you to read it (or have it read to you and explained to you). This study only includes people who choose to join. Please take your time to decide whether to participate or not and please feel free to ask any questions you may have concerning your role in this research.</p> <p>REASON FOR RESEARCH</p> <p>This research aims to understand and document the the choices made about asthma treatment by patients, and assess the potential impact of different providers of that treatment. I am interested in your experiences about your recent asthma treatment. I would like to ask you questions about how you are receiving your treatment; whether it is easy or difficult to get your asthma treatment and your choices regarding treatment</p>	

provider. I would be very grateful if you could spend some time talking with me. The interview will take about 30 – 40 minutes. Your participation is voluntary and you do not have to answer any questions you do not want to. Participating or not participating in this interview will not negatively affect any health services that you are currently entitled to, or those that are entitled to get in the future.

POSSIBLE RISKS

Some of the questions you are asked might make you feel uncomfortable. If you do not want to answer a question, you do not have to.

There will be an audio recording made of your participation in this study. You may feel uneasy and be afraid that others in your community may hear the recording. We will take steps to make sure no one hears the recording except research staff.

POSSIBLE BENEFITS

There are no direct benefits to you for taking part in this research. However, your participation may help us to understand the choices that people make regarding where they get asthma treatment and how potentially to improve the services offered. This study may also help to incorporate voices of asthma patients on influencing how and where asthma treatment is provided.

VOLUNTARY PARTICIPATION

You are free to decide if you want to be in this research or not. If you decide you want to leave the research after you enrol, it is ok. You may choose to leave the study at any time. If you leave, it will not affect your access to health services or any other aspect of your life.

CONFIDENTIALITY

In order to be able to know who you are we will also ask you some questions about yourself such as your age and education level, area of residence and so forth. We will record the talk on a digital recorder. This recording will make sure that we do not lose any of your valuable information. However for the purpose of confidentiality, avoiding other people to link the information that you share with us, we will not record your name anywhere after we finish participant recruitment. Your contact information will be destroyed at the end of this study. Also, we will not tell anyone in your community about your participation in this study. Although we will not write down your name, your answers may be published, for others to read, in booklets, journals, or websites. However, in these publications, there will be no names, so no-one will know that the words came from you.

When all study activities have finished, contracted access to the study data has been completed, and five years from study close-out has passed the audio data containing participant voices will be destroyed.

RESEARCH QUESTIONS OR CONCERNS

If you have any questions about the research, you can contact:

[Local contact details of head of research institution]

YOUR RIGHTS AS A PARTICIPANT

This research has been approved by the Khartoum ethics committee and the ethics committees of Lancaster University and the Liverpool School of Tropical Medicine. If you have any questions about how you are being treated by the study or your rights as a participant you may contact:

[Local ethics committee contacts]

VERIFICATION OF ORAL INFORMED CONSENT

The above document titled “Understanding the role of private providers in adult asthma treatment in Khartoum” describing the benefits, risks and procedures for this research study, has been read and explained to me the participant. I have been given an opportunity to have any questions about the research answered and have agreed to participate as a volunteer. Additionally, I certify that a second copy of this consent form provided to me for my personal records.

Participant Study ID Number (PSN)

Printed Name of Person Who Obtained Consent

Signature of Person Who Obtained Consent

Date

	<p>“Understanding the role of private providers in adult asthma treatment in Khartoum”</p> <p>INFORMED CONSENT</p>
	<p><i>Information given to participants:</i></p>
<p style="text-align: center;">Informed Consent Form for Enrolment to Survey</p> <p>STUDY PARTNERS</p> <p>EPILAB Khartoum, Liverpool School of Tropical Medicine (LSTM) and Lancaster University</p> <p>INTRODUCTION</p> <p>This consent form tells you about the research study that aims to understand and document the choices made about asthma treatment by patients, and assess the potential impact of different providers of that treatment. To be sure that you are well informed about your rights and what is being requested of you in this research, we are asking you to read it (or have it read to you and explained to you). This study only includes people who choose to join. Please take your time to decide whether to participate or not and please feel free to ask any questions you may have concerning your role in this research.</p> <p>REASON FOR RESEARCH</p> <p>This research aims to understand and document the choices made about asthma treatment by patients, and assess the potential impact of different providers of that treatment. I am interested in learning about the facilities and resources available for asthma treatment at your health facility. I would be very grateful if you could spend some time talking with me. The questionnaire interview will take about 30 – 40 minutes. Your participation is voluntary and you do not have to answer any questions you do not want to. Participating or not</p>	

participating in this questionnaire will not negatively affect any health services that you are currently entitled to, or those that are entitled to get in the future.

POSSIBLE RISKS

Some of the questions you are asked might make you feel uncomfortable. If you do not want to answer a question, you do not have to.

POSSIBLE BENEFITS

There are no direct benefits to you for being in this research. However, your participation may help us to understand the choices that people make regarding where they get asthma treatment and how potentially to improve the services offered. This study may also help to incorporate voices of asthma patients and providers on influencing how and where asthma treatment is provided.

VOLUNTARY PARTICIPATION

You are free to decide if you want to be in this research or not. If you decide you want to leave the research after you enrol, it is ok. You may choose to leave the study at any time. If you leave, it will not affect your access to health services or any other aspect of your life.

CONFIDENTIALITY

In order to be able to know who you are we will also ask you some questions about yourself such as your age and education level, area of residence and so forth. However for the purpose of confidentiality, i.e. avoiding other people to link the information that you share with us, we will not record your name anywhere after we finish participant recruitment.

Your contact information will be destroyed following the end of this study. Also, we will not tell anyone in your community about your participation in this study. Although we will not write down your name, your answers may be published, for others to read, in booklets, journals, or websites. However, in these publications, there will be no names, so no-one will know that the words came from you.

When all study activities have finished, contracted access to the study data has been completed, and five years from study close-out has passed the data containing your responses will be destroyed.

RESEARCH QUESTIONS OR CONCERNS

If you have any questions about the research, you can contact:

[Local contact details of head of research institution]

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This research has been approved by the Khartoum ethics committee and the ethics committees of Lancaster University and the Liverpool School of Tropical Medicine. If you have any questions about how you are being treated by the study or your rights as a participant you may contact:

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The above document titled “Understanding the role of private providers in adult asthma treatment in Khartoum” describing the benefits, risks and procedures for this research study, has been read and explained to me the participant. I have been given an opportunity to have any questions about the research answered and have agreed to

participate as a volunteer. Additionally, I certify that a second copy of this consent form provided to me for my personal records.

Participant Study ID Number (PSN)

Printed Name of Person Who Obtained Consent

Signature of Person Who Obtained Consent

Date

Participant Information Sheet (interviews)

Project Title:

Understanding the role of private providers in adult asthma treatment in Khartoum

Invitation:

You are being asked to take part in a research study on the choices made about asthma treatment by patients, and to assess the potential impact of different providers of that treatment.

Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what will be involved. Please take time to read the following information carefully and contact me if anything is unclear or you would like more information.

What will happen:

In this study, you will be asked a series of open ended questions about the choices made regarding asthma treatment and the reasons these choices were made.

Time Commitment:

The interview will take place at the Health facility and will take approximately 30 – 40 minutes.

Participants' Rights

You can decide to stop being part of the research study at any time and without explanation. You can ask that any data you have supplied be destroyed. You do not have to answer questions that you do not wish to and your name will be removed from the information and anonymised. It will not be possible to identify anyone from the study reports.

Benefits and Risks:

There are no direct benefits or risks to you for taking part in this research. However, your participation may help us to understand the choices that people make regarding where they get asthma treatment and how potentially to improve the services offered. This study may also help to incorporate voices of asthma patients and providers on influencing how and where asthma treatment is provided.

Contact for further information:

Rachael Thomson [add local EPILAB contact details]

Liverpool School of Tropical Medicine

r.thomson@liv.ac.uk

Participant Information Sheet (survey)

Project Title:

Understanding the role of private providers in adult asthma treatment in Khartoum

Invitation:

Multiple levels of influence affecting the utilisation of adult asthma services in the private sector in 215

You are being asked to take part in a research study on the choices made about asthma treatment by patients, and to assess the potential impact of different providers of that treatment.

Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what will be involved. Please take time to read the following information carefully and contact me if anything is unclear or you would like more information.

What will happen:

In this study, you will be asked a series of questions about the facilities and resources for asthma that are available at the health facility where you work.

Time Commitment:

The interview will take place at the Health facility and will take approximately 30 – 40 minutes.

Participants' Rights

You can decide to stop being part of the research study at any time and without explanation. You can ask that any data you have supplied be destroyed. You do not have to answer questions that you do not wish to and your name will be removed from the information and anonymised. It will not be possible to identify anyone from the study reports.

Benefits and Risks:

There are no direct benefits or risks to you for taking part in this research. However, your participation may help us to understand the choices that people make regarding where they get asthma treatment and how potentially to improve the services offered. This study may also help to incorporate voices of asthma patients and providers on influencing how and where asthma treatment is provided.

Contact for further information:

Rachael Thomson

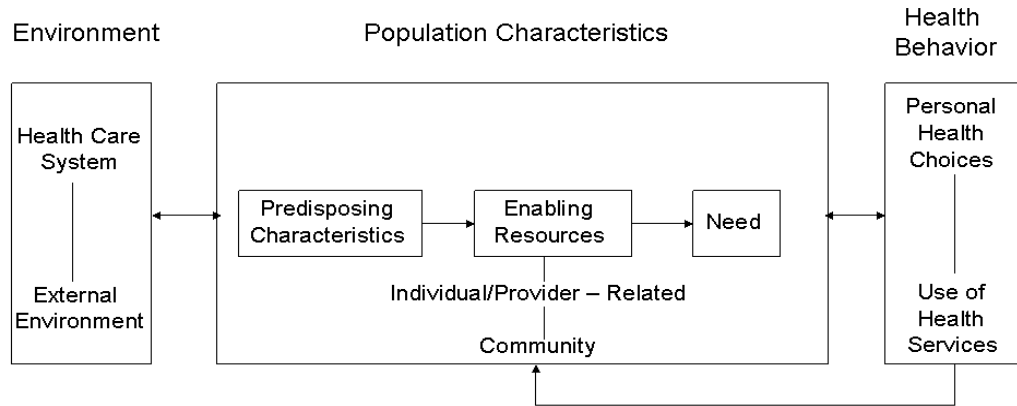
[add local EPILAB contact details]

Liverpool School of Tropical Medicine

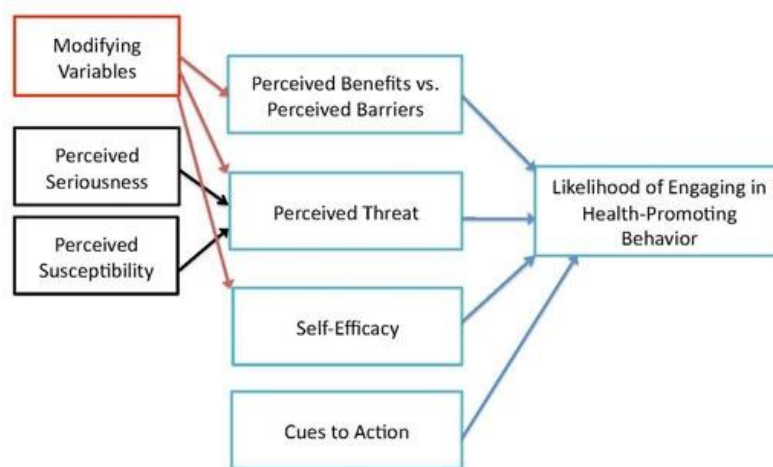
r.thomson@liv.ac.uk

Annex G: Health seeking models:

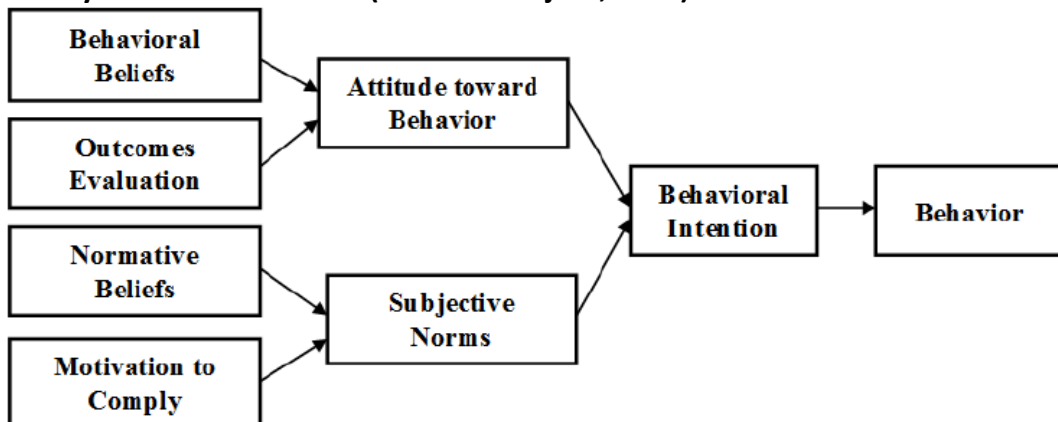
Andersen’s health seeking model (Andersen, 1995)



Health belief model (Rosenstock et al., 1988)



Theory of Reasoned Action (Fishbein & Ajzen, 2005)



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