

**THE COMPLEXITIES OF ATTENDING TB DIAGNOSTIC SERVICES FOR  
ADULTS IN RESOURCE POOR SETTINGS**

**Thesis submitted in accordance with the requirements of the  
University of Liverpool for the degree of Doctor of Philosophy by**

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**DECLARATION**

This thesis has not been submitted in any other application for a degree and is the result of my own  
work and composition.

To my husband: in grateful recognition of his unwavering support, discerning eye, far sightedness, wisdom, academic and nutritional sustenance.

To our children: for endless and beautiful diversions and reminding us how to take pleasure in the minutiae of everyday life.

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## Preface

The research presented here has its roots in two research studies on Tuberculosis. The first was a study aiming to optimise the use of smear microscopy for the diagnosis of adults with pulmonary tuberculosis in four countries. This study was being conducted by Prof Luis E. Cuevas (PI) and Drs Mohammed Yassin and Sally Theobald at LSTM and a number of partners in Nepal, Nigeria, Ethiopia, Yemen and Brazil and was funded by WHO. The study aimed to provide the scientific evidence to inform international policies on smear microscopy. At the time, I had not considered undertaking the PhD studies in this thesis; however, I had established links with the international partners through personal exchanges and contributed to the development of the protocol. While the research team was conducting these studies, an opportunity arose to apply for further funding to identify barriers to accessing tuberculosis diagnostic services. The funder, ESRC/DfID, expressed its interest in the letter of intention and I became an honorary member of the team preparing the full application. The application contained an opportunity to apply for a project linked scholarship for a doctorate in philosophy. Upon securing the ESRC/DfID funds, it became evident that this was an area of major research interest to me and after discussion with the team, it was decided I would put my name forward as a candidate. I was grateful to be selected. During the first year, I was an integral part of the team and developed the questionnaires, interview guides, consent forms and ethics applications, liaised with country partners and travelled to Yemen, Ethiopia and Nepal to prepare staff and initiate studies. At this juncture, I moved abroad with my family, due to my husband's sabbatical in WHO. Funds and the overall management of the award remained in Liverpool and I continued to oversee and give follow up to the studies from my new base, in partnership with the PI. The team in Liverpool had reduced in numbers and follow-up of activities grew more difficult. After discussion with my supervisors (Dr Sally Theobald (primary) and Prof Elizabeth Ettorre), I took the lead in processing the data collected in the first study for the cost analysis and subsequently for managing the data and assisting with the coordination of the ESRC/DFID studies, under the close guidance of the PI. Although this had not been my intended role, I am grateful for having had the opportunity to play an active part in the wider remit of the study and to my supervisors for allowing me to support the activities. In view of these evolving circumstances, the distinction between the wider research aims and my thesis became less clearly defined and the thesis became an integral part of the wider research study and will be the basis for preparing peer-reviewed publications.

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## ABSTRACT

**Background:** TB is a disease of poverty affecting disenfranchised populations. A major impediment to treatment access is the need to complete a diagnostic process that requires multiple visits to health services. An estimated one third of the cases occurring globally each year are never diagnosed. Addressing access barriers for TB diagnosis therefore is critical to increase access to treatment.

**Aims:** The study aimed to identify economic, social and cultural barriers hindering patients with symptoms of TB from completing the diagnostic process and, by extension, accessing treatment, with a view to assessing the gains to be made through the implementation of a screening process that could complete smear microscopy on the first day of consultation.

**Methodology:** Two large cross sectional studies were conducted among adults at first attendance for diagnosis. The first survey was conducted in Nigeria, Nepal, Ethiopia and Yemen and quantified the cost of attending diagnostic services, describing expenditure for the first and second day of attendance. Patients with expenditure ranking above the 75<sup>th</sup> centile were compared with patients with lower expenditure to identify risk factors for high expenditure. A screening score was developed by performing logistic regressions of these risk factors to identify patients with high expenditure. A second survey in Yemen and Ethiopia described adults' knowledge of services and the disease, service satisfaction and risk factors for defaulting. Further qualitative studies were then conducted in Yemen and Ethiopia comprising in depth interviews and focus group discussions with individuals who completed/did not complete the diagnostic process or who had registered/did not register for treatment.

**Results:** The most significant expenses incurred by patients for diagnosis were for clinic fees and transport. Many factors were associated with high expenditure. The main contributors for high cost across all study settings were attending the services with company and rural residency. Costs for first and second day attendance were comparable. The score to identify patients at risk of high expenditure achieved 54% and 69% sensitivity and specificity and its performance varied across settings. Most participants (particularly women) attended the services with companions – considerably increasing the cost of diagnosis. Many patients were unprepared for the duration of the diagnostic process. Women were perceived to face particular difficulties to access health services. Patients' reasons for defaulting diagnosis included the cost of the process, receiving negative smear results (especially in Yemen) or having a clear chest X-ray on the first day and receiving misleading or misinterpreting the information given by staff. In some settings patients had to pay additional unofficial fees and were often referred to private services. Patients found non-TB medication and additional tests in the private sector prohibitive. Many patients highlighted opportunity costs for diagnosis and treatment. In Ethiopia, the lure of attending private sector services and poor staff attitude featured strongly.

**Conclusion:** Patients in resource poor contexts face multiple barriers to attending and completing TB diagnosis. These barriers disproportionately affect women and are mediated by sociocultural norms. Although structural and health systems reform is needed to address many of these barriers, some could be resolved at local level with education, approaches that are patient-centred and respectful, free provision or clear charging policies and more flexible opening hours that minimise opportunity costs. A same day smear microscopy process could assist patients by reducing direct and opportunity costs if diagnostic services could complete the diagnostic process the same day of consultation.

## Abbreviations

AFB	Acid fast bacilli
AOR	Adjusted Odds Ratios
AUC	Area Under the Curve
CDC	Centers for Disease Control
CDR	Case detection rates
CI	Confidence Interval
Col%	Column percentage
DFID	Department for International Development
ESRC	Economic and Social Research Council
ETB	Ethiopian Birr
HC	Health centre
FGD	Focus Group Discussion
HBCs	High burden countries
HIV	Human immunodeficiency virus
HEWs	Health Extension Workers
IDI	In Depth Interviews
IQRs	Interquartile ranges
LMIC	Low and Middle Income Countries
LR	Logistic regression
MPI	Multidimensional Poverty Index
NGO	Non-governmental Organisation
NTI	National Tuberculosis Institute
NTP	National Tuberculosis Programme
OECD	Organisation for Economic Co-operation and Development
OPHI	Oxford Poverty and Human Development Initiative
OR	Odd Ratio
PTB	Pulmonary tuberculosis
Q	Quotation
SD	Standard Deviation
SIGI	Social Institutions and Gender Index
Sic	<i>sic erat scriptum</i>
SNNPR	Southern Nations, Nationalities, and Peoples Region
TB	Tuberculosis
TDR	Tropical Diseases Research Programme
US	United States
WHO	World Health Organisation
YER	Yemeni Rial
ZMC	Zankli Medical Centre

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## Chapter 1

### Introduction

*“Your tale, sir, would cure deafness.”*  
— William Shakespeare, *The Tempest*

Tuberculosis (TB) is a disease of poverty. Most cases of the disease across the world occur among the most disadvantaged populations. Although *Mycobacterium tuberculosis* was identified more than a century ago and the first antituberculosis drugs more than 60 years ago, TB remains a leading cause of morbidity and mortality (Lawn and Zumla 2011; Lienhardt et al. 2012). Controlling and eventually eradicating the disease is complex, since those contracting the disease range from prisoners and migrant workers, to adults with smoking, alcohol or drug addictions and diabetes in semi-industrialised countries, to the very poor in developing countries (Lawn and Zumla 2011; Lienhardt et al. 2012). It is often debated whether socioeconomic development may have a greater impact on reducing TB incidence than the implementation of disease control measures through vertical programmes (Aditama 1991; Al-Maniri et al. 2007; C. Dye et al. 2009; Irawati et al. 2007; Soemantri et al. 2007).

Emphasis for TB control has been placed on the development of improved vaccines, diagnostics and treatment courses. Although the need for these tools is indisputable, the obstacles facing adults suffering from TB go beyond the technological (Benatar and Upshur 2010; Keshavjee et al. 2011). The barriers to accessing diagnostic services are complex, ranging from social stigma and belief in the ability of traditional remedies to cure the disease, to physical, logistic and economic constraints, through to patterns of behaviour shaped by gender roles (Storla et al. 2008). Despite the increasing body of evidence suggesting that improving access to diagnostic services is key, most studies employ different methods across settings and findings are rarely comparable.

This doctoral study, which was funded by the Economic and Social Research Council (ESRC) in partnership with the Department for International Development (DfID), was designed to identify barriers preventing TB suspects from completing the diagnostic process and to assess whether accelerated diagnostic schemes would lead to improved completion rates for diagnosis and registration for treatment in Ethiopia, Nepal, Nigeria and Yemen. This thesis aimed to:

- Assess the cost of attending TB diagnostic services and gauge whether an accelerated diagnostic scheme would result in significant cost savings, using data collected during a WHO funded clinical trial.
- Identify populations characteristics associated with high service attendance costs.
- Assess whether an accelerated TB diagnostic scheme would lead to improved completion rates for diagnosis and registration for treatment.
- Identify barriers and enablers for completion of diagnosis and registration for treatment across several countries and describe commonalities and differences in the patient experience across settings.
- Obtain suggestions for the improvement of health services from health staff and patients in order to facilitate patient completion.

The study was conducted in 4 countries with a high incidence of TB and sited at *Bushullo Major* and *Awassa Health Centres* in Awassa, Southern Nations, Nationalities and People's Region, Ethiopia; *Tribhuvan University Teaching Hospital* and *Dirgh Jeevan Health Care and Research Centre* in Kathmandu, Nepal; *Wuse District Hospital* (and *Zankli Medical Centre TB Research Laboratory* for sputum processing) in the Federal Capital Territory of Abuja, Nigeria and the *National Tuberculosis Institute* in Sana'a, Yemen.

The thesis comprises eight chapters. **Chapter 2** provides an overview of the literature on the topic, beginning with the prevalence of TB in resource poor countries, barriers to accessing health services, health seeking behaviour and the cost of illness, diagnosis and treatment. The review surveys the

international literature and makes reference to literature pertaining to the individual country contexts where available. **Chapter 3** lays out the methodological approach to the study and the set of studies conducted. **Chapter 4** reports on a survey of patients' costs. **Chapter 5** presents a survey of barriers and enablers to attendance set in Ethiopia and Yemen. **Chapter 6** describes a qualitative study of patients' experience at diagnosis in Yemen and **chapter 7**, a qualitative study of patients' experience at diagnosis in Ethiopia. Each results chapter has a discussion of issues pertaining to the findings. The thesis is then concluded by an overall discussion of the combined study findings in **chapter 8**, allowing for contrast and comparison of methods in the context of the international literature and reflecting on changes that could be made to service delivery.

## Chapter 2

### Literature review

Tuberculosis TB is a disease associated with poverty (WHO 2005) and is one of the main causes of adult death and morbidity due to infection in developing countries. Figures from 2010 show an estimated mortality of 1.45 million and 8.8 million new cases occurring worldwide, of which 1.1 million were among people infected with HIV (WHO, 2011b). Eighty percent of incident cases and 90% deaths occur in low and middle income countries (LMIC) (WHO, 2011b), predominantly among the poorer sections of society (Lönnroth et al. 2010b). Since 2006, the global disease burden has shown a very slow decline, when the decrease in the incidence rate (which peaked in 2004) began to exceed the world population growth rate and TB mortality rates have also been falling since 1990 (WHO, 2011b). These advances are attributed to increased investment and multilateral efforts to improve control of the disease from the perspective of diagnostics, treatment and health systems development in the last decades (Lawn and Zumla 2011). Yet although stemming the rising disease incidence marks a significant landmark, TB remains incontestably one of the major public health challenges of our times.

#### *Disease distribution*

Most of the estimated incident cases of TB in 2010 occurred in Asia (59%) and Africa (26%), with smaller proportions in the Eastern Mediterranean Region (7%), the European Region and the Americas (WHO, 2011b). Twenty-two countries with the highest disease burden - known as high burden countries (HBCs) - have been given priority by the World Health Organization (WHO). They include Ethiopia and Nigeria (two of our study settings). Overall, the HBCs account for 81% of incident cases worldwide (WHO, 2011b). As well as a decline in incidence rates, prevalence rates are also falling globally and two out of six World Health Organisation (WHO) regions have halved, or are on track to halve, 1990 prevalence rates by 2015 in line with the Stop TB Partnership's target (WHO, 2010b). It should be noted at this point that obtaining an accurate estimate of disease burden is

problematic, since few national prevalence surveys have been undertaken to date, although this is starting to change. Progress in the Eastern Mediterranean, European and South-East Asia regions, although considerable, is likely to fall short of meeting the target and reductions in the African Region are much more modest (WHO, 2011b). Achieving a halving of mortality rates in the African region also looks unlikely. Nevertheless, mortality rates are falling globally, including among 21 of the 22 HBCs. Yemen and Nepal, our 2 other study sites, have a high incidence of TB, but are not classed as HBCs due to their small population size.

The estimated epidemiological burden of TB for 2010 (rate per 100,000 population) in the 4 study settings, is shown in table 2.1. Ethiopia showed the highest mortality, prevalence and incidence rates, followed by Nepal, Nigeria and Yemen. Following the global trend, incidence rates in Ethiopia and Yemen appear to be falling, have remained constant in Nepal since 1990, while in Nigeria they have risen slightly since 2009, following a previously sharp fall (although estimates of TB incidence in Nigeria carry a high margin of uncertainty) (WHO, 2011b). The prevalence of HIV in incident cases was high in Nigeria (25%), low in Nepal and not well documented in Ethiopia and Yemen. The proportion of incident (new and relapse) cases detected in Ethiopia, Nepal, Nigeria and Yemen was 72%, 72%, 40% and 76%, respectively. Thus Nigeria had one of the lowest case detection rates (CDRs) of the 22 HBCs, with one of the highest disease burdens (320,000 cases). Ethiopia had a fairly low percentage of new cases of pulmonary TB that were sputum smear-positive (46%).

#### *Challenges to disease control*

The many and complex reasons that the TB epidemic persists, include continued widespread poverty and malnutrition, the knowledge shortfall surrounding the transmission and pathogenesis of the disease, the limitations of affordable and accessible diagnostic tools to date, weaknesses in health systems, the growth in HIV-associated TB, the emergence of drug-resistant strains and the absence of an effective vaccine (Lawn and Zumla 2011).

**Table 2.1 Estimated epidemiological burden of TB in the study settings, 2010 (rate per 100,000 population)**

Country	Population (millions)	Mortality rate excl. HIV	Prevalence rate	Incidence rate	CDR (%)	HIV prevalence in incident cases
Ethiopia	83	35	394	261	72	-
Nigeria	158	21	199	133	40	25
Nepal	30	21	238	163	72	2.9
Yemen	24	5.9	71	49	76	-

Source: WHO Report 2011, Global Tuberculosis Control 2011

Another obstacle to progress of perhaps greater magnitude is the number of symptomatic adults that remains undetected in the community (an estimated 35% of new and recurrent cases) (Dye et al. 1998a; WHO, 2011b). Case detection rates have improved since the introduction of the DOTS strategy in 1995. However, information on the number of cases that continue to be missed by surveillance systems is incomplete, due to individuals with cough not seeking formal healthcare, not receiving a formal diagnosis, or absence of reporting systems for diagnosed cases among some non-governmental organisations (NGOs) or private sector providers, amongst others (WHO, 2011b).

A related problem of similar dimensions is delay in achieving a diagnosis. Delay in attending, or non attendance, at a formal health facility for diagnosis is a significant threat to control, as it spreads infection. Patients attend with more advanced disease, which increases mortality and the burden of the disease (Lawn and Zumla 2011). Symptomatic individuals present late to health services due to a variety of factors such as rural residence, logistical constraints, economic reasons, illiteracy, lack of awareness and the social stigma surrounding the disease. Use of traditional medicines, low access to healthcare and limited choice of services, prior and repeated consultations with private providers and unqualified or low level healthcare providers without achieving a correct diagnosis, are further reasons for delay (Bates et al. 2004a; Sanou et al. 2004a; Storla et al. 2008; Yan et al. 2007). These factors do not operate uniformly, but vary according to individual circumstances and the local or national context in which they occur. Indeed, a risk factor for delay in one setting has been found to

decrease the likelihood of delay in another. For example, females are at increased risk of diagnostic delay in several settings, including Yemen; while in others, such as Ethiopia, the opposite has been reported (Storla et al. 2008). In studies of patient delay among TB suspects attending diagnostic services in Ethiopia and Cameroon (Cambanis et al. 2005; Cambanis et al. 2007), associated factors were predominantly economic and related to the patient being the principal earner in the family. In both countries, many patients were obliged to borrow money to attend services and some had to sell personal assets. Risk of delay is likely to be intensified for the individual if several risk factors are present.

Studies variously make a distinction between patient delay, provider delay and total delay (Bai and Xiao 2004; Deng et al. 2006; Fei et al. 2006; Gele et al. 2009; Huong et al. 2007; Hussen et al. 2012; Mahendradhata et al. 2008; Meyssonier et al. 2012; Ngangro et al. 2012). The study designs, however, differ greatly in terms of sample size, criteria for inclusion or exclusion of patients such as pulmonary or extra pulmonary TB, and the categorisation and definition of delay. The terminology 'patient' and 'provider' delay seems misleading and the distinction between the two somewhat arbitrary, in that patient delay does not depend solely on the patient's decision to attend, but also on the availability of health services. Similarly, provider delay is not uniquely related to the actions of the health provider, but is in part a product of the patients' capacity to attend, shaped by their personal circumstances. In many studies, the risk factors for patient and provider delay are similar, which is perhaps reflective of this blurred distinction. Provider delay sometimes refers to the period of time between presentation at TB diagnostic services and treatment initiation and at other times between patient presentation and the moment of reaching a diagnosis. The categorisation of prolonged delay, measured in the number of weeks delayed, also differs, and studies variously identify risk factors for delay, long or very long delay, meaning that risk factors may diverge according to this moving cut-off.

Despite these methodological constraints, risk factors found to be independently associated with longer patient delay in diagnosis in different settings in Asia and Africa in the literature cited above, include: socio-demographic factors such as rural residence and distance to the health facility; female gender and belonging to an ethnic minority; low economic status, low income, illiteracy, low biomedical knowledge and, counter intuitively, secondary level education (Ngangro et al. 2012). Other factors are related to patients' previous health seeking, such as prior visits to a traditional healer, private clinic or pharmacist, not being referred and advanced disease status on arrival. The association of patient delay with private medicine is an important one. A surprisingly high proportion of people in resource-poor countries seek care from private pharmacies, other private sector providers and purchase anti-TB medicines in the private sector (Karki et al. 2007; WHO, 2011b). There are several reasons for this. Private practitioners may be the sole service provider in a community. In addition, for-profit providers place importance on client satisfaction and often rely on marketing strategies to promote their services, thereby creating a perception, whether correct or not, of superior quality. Unfortunately, private practitioners are rarely equipped to diagnose TB and patients are often referred late, or not at all, to appropriate diagnostic services. Independent risk factors for provider delay in these studies show wide overlap with those for patient delay, with rural residence, female gender, low educational level, illiteracy, prior consultation and continued contact with a traditional healer, primary level health provider, private clinic or pharmacist being identified. An additional risk factor for provider delay is the stigma associated with TB and more unusually, prior health education on TB (Bai and Xiao 2004). Risk factors for 'total' delay (the sum of patient and provider delay) show many similarities to risk factors for patient and provider delay; namely, rural or remote residence, low income, female gender and initial visit to the private sector. Additional risk factors are being married, being middle aged and having non-specific symptoms such as cough. The causative path for many of these factors is not immediately obvious. The presence of more disease specific symptoms such as haemoptysis, weight loss, fever and chills on the other

hand, have been identified as independent risk factors for shorter diagnostic delay (Meyssonnier et al. 2012).

### *Gender and TB*

Women are known to face multiple barriers to accessing healthcare, including TB diagnostic and treatment services, in resource poor countries (WHO 1991, 2004, 2005) and a higher proportion of notified TB cases (63% or 64%) globally are among men (Ottmani and Uplekar 2008). The reason for this disparity is a matter of considerable debate; to what extent the gender differential in case notification is due to sex, as a biological determinant, or gender, as a socio-cultural determinant. Are fewer women identified due to access barriers or disease epidemiology (Ottmani and Uplekar 2008)? There is a shortage of national TB prevalence surveys of the general population; nevertheless a review of prevalence surveys in several countries showed that prevalence is higher among men in many countries (Borgdorff et al. 2000; Hoa et al. 2011).

The picture is complex. There is some evidence that men have a higher biological risk of developing active TB than women (Gustafson et al. 2004; Kolappan et al. 2007), while others have found that this is only true of men over 40 years of age, with more women progressing from latent to active disease in their reproductive years (Conolly and Nunn 1996; Holmes et al. 1998). Women have smaller respiratory muscles for expectoration and thus are less likely to produce good quality specimens and high numbers of acid fast bacilli (AFB) in sputum (Begum et al. 2001; Khan et al. 2007). Diagnostic tests may therefore be less sensitive in women (TDR 2006). The clinical presentation of the disease also varies between men and women. Men are more likely to have haemoptysis (Long et al. 2002), and more extended lung involvement at the time of diagnosis (Thorson et al. 2007). Lawson et al. noted that the human immunodeficiency virus (HIV) has further complicated these interactions, as HIV has sex and age specific patterns of infection, and the virus overrides the immune response differences associated with sex (Lawson et al. 2010). Men have also

been found to be more likely to default from treatment, be re-treated for TB and to die (Jimenez-Corona et al. 2006).

In terms of socio-cultural factors influencing TB sex distribution, in many societies, women have reduced access to services (Begum et al. 2001; WHO 1991). This can be seen as a consequence of women's disenfranchisement in the social, political and economic spheres. Women's control of household resources and healthcare decisions and freedom to travel are often curtailed and women's health is given less priority compared with men's (Chard 2009; Liefoghe et al. 1995; Onifade et al. 2010; WHO 2005). Moreover, in many societies, the triple jeopardy of housework, childcare and paid employment leaves women little time to care for their own health needs (Rajeswari et al. 1999). Women may have a different perception and less knowledge of the disease than men (Hudelson 1996; Wang et al. 2008; WHO 2004) and more limited awareness of TB diagnostic and treatment facilities (Wang 2008). Women may also receive differential treatment by health providers (Ahsan et al. 2004; Thorson and Diwan 2001). Even where TB patients consider that they are given equal treatment by the TB control programme or public health providers (Onifade 2010), there is an argument that health professionals should go beyond equal treatment of female patients and positively discriminate for their specific needs and greater socio-economic vulnerability (Thorson 2004). All these factors combine to result in different service utilisation, with more symptomatic men attending health services and undergoing sputum examinations and a higher number of males being diagnosed with pulmonary TB (PTB) than females (Begum et al. 2001; Ganapathy et al. 2008; WHO 2004).

Health seeking behaviour may also differ. A study in Vietnam showed that symptomatic women first sought private care or self treated, while men waited until their health had reached a critical stage and went directly to public services (Johansson et al. 2000). The principal reason for delay among women was fear of social isolation from the family or community; while men were fearful of the cost of diagnosis and treatment. In other studies, women have been found to be more likely to seek

healthcare than men, but to consult lower level health facilities (Thorson et al. 2000; Wang et al. 2008). Being female also has an association with diagnostic delay (WHO 2005).

The fear and stigma associated with TB have been found to have a greater impact on women, leading to economic and social vulnerability (Hudelson 1996), such as rejection, divorce or reduced marital prospects, especially where levels of female literacy and education are low (Conolly and Nunn 1996; WHO 2005). A sizeable proportion of female TB patients in rural Bangladesh reported relationship problems with their spouse and family members post diagnosis (Ahsan et al. 2004) and women in Peru experienced disproportionately adverse psychosocial and economic consequences of a positive diagnosis than men (Onifade et al. 2010). For this reason, women fear stigma (WHO 2005) and many conceal their symptoms, instead of seeking healthcare (Conolly and Nunn 1996).

This is not to say that men do not also face barriers to access. TB affects the most economically productive age group (Clark 1996; WHO 1995, 1996) cited in (Rajeswari et al. 1999) and men of working age have been found to delay attendance at TB diagnostic services and to default from treatment, due to concerns about losing employment (WHO 2005). Men may also have increased exposure to certain TB risk factors such as alcohol and smoking (Watkins and Plant 2006). The global male preponderance of TB incidence hides many variations and exceptions; for example in Iran and Afghanistan, the notified incidence rate of smear positive TB is higher for females (Ottmani and Uplekar 2008). The sex distribution of notified TB cases varies not only across regions and countries, but also within countries and perhaps even within districts (Ottmani and Uplekar 2008) and socioeconomic groups. There is a call to understand the nuances and subtleties of these differences in order to address the problem of gender disparity, with a view to improving TB control (Ottmani and Uplekar 2008). In summary, gender disparities in TB are context specific and are likely to result from the combined effects of biological and socially-constructed gender patterns (Diwan and Thorson 1999; WHO 2004), which are further confounded by HIV (Lawson et al. 2010).

*TB as a disease of disadvantage and inequity*

... 'while TB is not exclusively a disease of the poor, the association between poverty and TB is well established and widespread'; such was the conclusion of a symposium on TB and poverty convened by the Stop TB Partnership in 2002 (WHO, 2002). The link between TB and poverty, manifest in the higher rates of TB among the most disadvantaged and marginalised subsections of society, has been observed for two centuries, although historically it has been documented principally in Europe and the United States of America (Cantwell et al. 1998; Holtgrave and Crosby 2004), rather than in the low-income countries (Akhtar et al. 2007; Antunes and Waldman 2001; Sanghavi et al. 1998; Tupasi et al. 2000) in which it is now endemic (Lienhardt et al. 2012; Lönnroth et al. 2010b; WHO 2005). Indeed, low-income countries are estimated to bear 20 times the disease incidence of their high-income counterparts (WHO 2005). Today there is greater (albeit incomplete) insight into the nature and dynamics of the relationship between TB and poverty, as well as a realisation that the relationship is not with economic poverty alone. The most vulnerable populations across the world stand at greater risk of TB infection (Basta et al. 2006), disease development and adverse illness outcome (Lönnroth et al. 2009). Populations that are living or working in overcrowded and inadequate conditions, are malnourished, co-infected with other diseases such as HIV/Aids and migrating to or from high-risk populations are at increased risk of infection (Ho 2004; Lönnroth et al. 2009; Lönnroth et al. 2009, 2010b). Some isolated ethnic communities that have until recently escaped exposure to the disease, also stand at increased risk (WHO 2005). Although a third of the world's population is estimated to have been infected with TB, only 10% will progress to active disease (Lawn and Zumla 2011), of which a high proportion will originate from disadvantaged subpopulations such as refugees, prisoners, the urban poor and remote rural communities (de Alencar Ximenes et al. 2009; Harling et al. 2008). There are also indications of differences in treatment outcome by socioeconomic strata (Dewan et al. 2004; Greene 2004). The poorest (sections of) society are often locked in a cycle of poverty and ill-health. The poor are at increased risk of TB infection, the disease exacerbates poverty at individual and national level and leads back to increased risk of infection (Lönnroth et al. 2009).

Quite apart from the humanitarian imperative to identify the most vulnerable groups and support them from the point of reducing the risk of infection through to diagnosis and cure, are the economic and health benefits of so doing. The populations most at risk constitute reservoirs of disease transmission for their families, friends and wider contacts after onset of symptoms, as well as potential sources for the development of drug resistance, due to their reduced capacity to obtain a correct diagnosis and complete the treatment course. Moreover, the economic cost of lost productivity and a heavier caseload for national health systems cannot be underestimated.

The allocation of scarce public health resources in low-income countries has often been interpreted, or presented, as a tension between meeting the health needs of the majority who attend diagnostic and treatment services and a minority of 'hard-to-reach' individuals or subgroups that remain in the community (Jochem and Walley 1999; Singh et al. 2002). More recently, there has been a realisation that the number of adults that are undetected at home, either attending health services after weeks or months of spreading the disease, or not at all, is not a marginal issue, but lies at the heart of the failure to significantly reduce the disease burden. This has led to attempts to turn the problem on its head and explore ways of detecting cases early to reduce transmission rates and to prevent progression from infection to disease. When taken to their logical conclusion, reducing the risks of infection, progression to disease, absence of a formal diagnosis and default from diagnosis or treatment, all point to the need to tackle the root causes of health inequity; namely, poverty. Clearly, the health sector can make an important contribution to poverty reduction, but as one player among intersectoral efforts at national and international level (Lönnroth et al. 2010b).

TB adversely affects the sections of the population that are the most disadvantaged not just in economic terms, but also relative to rights of citizenship, health, education and social and political capital (WHO 2005). Attempts to reduce economic poverty, however comprehensive and strategic, would not be sufficient to have a significant impact on reducing the burden of disease in low income countries. Economic development alone can serve to perpetuate or aggravate inequalities, through

the changes in demography and lifestyle that accompany rapid industrialisation and urbanisation. These changes include migration, modified diet and increased alcohol and tobacco use, which can lead to health complications including obesity, diabetes, liver and lung diseases. Economic development has the potential to reduce TB incidence, if accompanied by equitable distribution of income, health and educational resources (Gilson 2007; Kjellstrom 2007; Popay 2007) cited in (Lönnroth et al. 2010b).

### *Costs*

There is general recognition that despite a principle of the right of universal access to free TB treatment, *treatment* is the last of a long and sometimes tortuous three-part journey of expenditure on healthcare for many patients, preceded by the period of *'help-seeking'* between onset of symptoms and *diagnosis*. Moreover, the cost of medication constitutes just one subcomponent of patient costs related to treatment. For many patients and their households, the economic cost of the disease is quite simply devastating (Ukwaja et al. 2012; Umar et al. 2012). Patients use savings, receive financial assistance from relatives and members of the wider community, take out bank loans, sell property and incur debts in order to fund the cost of illness (Kamolratanakul et al. 1999; Rajeswari et al. 1999; Ukwaja et al. 2012). TB patients find themselves in a poverty trap of incurring increased expenditure, while experiencing a reduction in income (Mauch et al. 2011).

There is a growing body of literature documenting the cost of TB services for the patient, known as 'patient costs' in urban (Kemp et al. 2007; Umar et al. 2012) and rural settings (Liu et al. 2007; Zhang et al. 2007), public hospital (Vassall et al. 2010) and health centres (Rajeswari et al. 1999), which complements a previous focus on the cost of TB to the health provider (Kamolratanakul et al. 1999b). Indeed, some authors have compared the proportion of cost borne by the patient with that shouldered by the health provider (Othman et al. 2012; Wyss et al. 2001). Studies often describe pre-treatment and treatment (Lönnroth et al. 2007; Vassall et al. 2010), pre-diagnostic (health-seeking) and diagnostic attendance, direct and indirect costs (Kemp et al. 2007; Umar et al. 2012).

Many authors calculate costs relative to estimated (household) income or average national income per capita (Aye et al. 2010; Vassall et al. 2010), to give an indication of the financial burden of the illness on the patient or their families in real terms and describe the costs experienced by socioeconomically disadvantaged groups (Kamolratanakul et al. 1999b; Kemp et al. 2007; Lonnoth et al. 2007; Zhang et al. 2007). The cost of health-seeking before attendance for diagnosis incurred in the private, informal or primary healthcare sectors and self-treatment through traditional remedies is documented in the literature (Lonnoth et al. 2007); as are the costs associated with treatment (Kamolratanakul et al. 1999a). Pre-treatment or pre-diagnostic costs have been found to outweigh the cost of treatment (Ukwaja et al. 2012). The total cost of illness due to TB is also described and comprises the cost of help-seeking, investigations, displacement, medication and loss of household income (Kamolratanakul et al. 1999; Rajeswari et al. 1999; Wyss et al. 2001). Despite the volume of studies, there is a lack of consensus on the most appropriate method to calculate patient costs. In an attempt to standardise methodological approaches, Mauch et al. have recently developed a tool to assess economic barriers to attendance at diagnostic and treatment services for use by TB control programmes, which was tested in Kenya and could merit further attention (Mauch et al. 2011).

The review of literature on costs in this chapter explores the direct (out-of-pocket) and indirect (opportunity) patient costs associated with attendance at formal diagnostic services, since this is the time period of interest to the study. In fact, there are few studies that isolate the costs associated with attendance at TB diagnostic services from those incurred before diagnosis or during treatment. The different cost components associated with diagnosis detailed in studies to date include: **direct costs** - *medical* (clinic fees or registration costs, cost of investigation or consultation, diagnostic tests and medication) and *non medical* (transportation, food and accommodation for patient and companion(s)) and **indirect costs** - loss of income for patient and household due to lost work days, incapacity to work or forced changed of occupation and substitution costs (the cost of replacing the patient in their duties).

The cost of attendance is a major barrier to accessing TB diagnostic services (Aye et al. 2010) and low-income groups have been found to be less likely to seek professional care for their symptoms (Zhang et al. 2007). Some studies have found that public expectation of the cost of attendance is higher than the actual cost (Liu et al. 2007), which might exacerbate non attendance in certain settings. Charging policies by public health facilities vary, since they are set by national, regional or local control programmes. Clinic fees can be considerable in some health settings, but elsewhere minimal or even free of charge. Many public (as well as private) health facilities charge for investigations, a cost which can be substantial (Karki et al. 2007). Even if clinic fees are low or free, there is growing awareness of the non medical and indirect costs associated with attendance for diagnosis (Rajeswari et al. 1999). In Nigeria, where the National Tuberculosis Programme (NTP) provides free diagnostic testing, patients nevertheless reported considerable patient expenditure (before, during and after diagnosis) for travel, registration and consultation fees, clinical examinations (such as X-rays) and food, which could be unaffordable for many (Umar et al. 2012). Although methods vary greatly, in India, patient costs were estimated to be 193% of the monthly income of a manual labourer (John et al. 2009) and in Zambia, 48% of patients' median monthly income (Aspler et al. 2008). In a small cross-sectional survey in urban Malawi, where public health services were provided free of charge and were accessible within a 6 km radius, the direct costs (including transportation and subsistence) and opportunity costs for the patient and their households were substantial (Kemp et al. 2007). The cost of transport is one of the most important direct costs and, although higher in rural areas, can still be considerable in urban areas (Cambanis et al. 2005a; Karki et al. 2007; Othman et al. 2012; Wyss et al. 2001). Indirect costs resulting from the inability to work, or lost work time, have been found to be more important than direct costs in studies documenting the total cost of illness to the patient, as reported by Wyss et al. in urban Tanzania, Othman et al. in urban Yemen and Mauch et al. in Kenya (Mauch et al. 2011; Othman et al. 2012; Wyss et al. 2001).

In some settings, the total cost of TB care (diagnostic and treatment phases) has been found to be higher for female patients. A study in Nepal suggested this was due to the higher cost of transportation for females, in a culture in which females were required to travel with an escort (Karki et al. 2007). In others, female expenditure has been found to be higher relative to lower female income, rather than higher in real terms (Mauch et al. 2011).

It is noteworthy that the medical and non medical direct and indirect costs of TB will also be met by adults that will remain undiagnosed and that suffer from an illness other than TB. Many symptomatic adults will spend a significant proportion of their resources and incur loss of household income due to illness, without undergoing the recommended diagnostic tests (Zhang et al. 2007). Likewise, the majority of adults that attend diagnostic services will be diagnosed as TB negative, despite incurring similar expenditure to their TB positive peers. Of these, some will be given an alternative diagnosis and/or prescription and recover; others will be referred for further tests elsewhere; some will be false negatives, meaning that their symptoms will continue and may or may not resolve themselves, and a small proportion will return home without knowing the cause or remedy for their condition, despite considerable financial expenditure. In a large-scale study in rural China, the poorest were the least likely to seek professional care and to receive appropriate treatment, although low-income groups carry the highest disease burden and highest relative costs (Zhang et al. 2007).

### *Stigma*

TB carries strong social stigma, perhaps more so than for other diseases, and can be especially severe for some individuals such as the poor, patients co-infected with HIV and women (Cambanis et al. 2005a; Eastwood and Hill 2004; Gebremariam et al. 2011; Liefoghe et al. 1995; Long et al. 2001), who may already be the objects of discrimination. Notwithstanding, the formal assessment of social stigma attached to TB has received much less attention to date than that of other diseases (Macq et al. 2006). Stigma may be perceived or experienced (Gray 2002) and may be expressed at individual,

community or institutional level. Perceived (known as 'felt' or 'internal') stigma can lead patients to isolate themselves from others through fear of adverse social consequences. Experienced ('enacted' or 'external') stigma constitutes discrimination against a person with a known or suspected illness and their family by other(s) and is distinct from the reasonable precautions taken by another to avoid contracting the disease. Enacted stigma may not be born of any malicious intention; but rather of fear of and misconceptions resulting from lack of knowledge. In the context of TB, as a serious illness that can endanger lives, the disease is perceived by many to be incurable (Liefoghe et al. 1995). In Ethiopia, the vernacular term for TB is also used to denote lung cancer. At the same time, lay knowledge of the contagious nature of the disease (Baral et al. 2007; Dodor et al. 2008; Ngamvithayapong et al. 2000) and of its prevalence among marginalised populations such as prisoners, the poor and those infected with HIV (Baral et al. 2007; Dodor et al. 2008; Eastwood and Hill 2004; Johansson et al. 1999; Ngamvithayapong et al. 2000), are likely to have contributed to the stigma surrounding it (Kipp et al. 2011). Manifestations of external stigma can take the form of rejection from family or friends, the breakup of marriage, engagement and reduced marriage prospects, loss of employment, unfair treatment by health professionals and ultimately lead to an erosion of civil rights (Atre et al. 2011; Baral et al. 2007; Gibson et al. 1998; Liefoghe et al. 1995; Somma et al. 2008). Self stigma can be just as damaging (Gray 2002). In urban Ecuador, patients felt shamed merely by being tested (Armijos et al. 2008). In a study in Pakistan, patients denied a diagnosis of TB and rejected treatment (Liefoghe et al. 1995). In rural India, male and female patients carried the psychological burden of unfulfilled social responsibilities (Atre et al. 2011).

Stigma can adversely affect access to TB health services by symptomatic adults who feel unable to disclose their illness, or who are ostracised, at home, at work or in health institutions, and therefore do not attend diagnostic services, attend at an advanced stage of illness, or cannot complete the full treatment course (Baral et al. 2007; Long et al. 2001; Rubel and Garro 1992). Many TB suspects and patients undergo a process of denial, in the hope that they will recover without treatment. For the majority of patients, attendance for diagnosis or treatment requires considerable support and

planning, in terms of funding, transportation and finding cover for duties at home or at work.

Seeking healthcare singlehandedly therefore is fraught with difficulty and for many - among them women, children and vulnerable groups - is not feasible. In addition, only about 10-20% of patients that attend a diagnostic service are ultimately diagnosed with TB. It is therefore easy to imagine that an individual with few resources might prefer to postpone the time of consultation, given the cost implications, possibility of marginalisation and eventual cure without treatment. The effects of stigma, whether perceived or actual, can lead to low self-esteem, or depression at the sufferers' loss of social status and inability to perform their usual duties (Link and Phelan 2006).

The degree and manifestations of stigma vary across national and local contexts (Somma et al. 2008; Van Rie et al. 2008) and are likely to reflect the general and health education and the socio cultural context (Johansson et al. 2000; Sengupta et al. 2006). In a setting in Pakistan, where women are economically dependent on their husbands, TB treatment was regarded as incompatible with pregnancy and, since pregnancy was believed to increase the risk of relapse, disclosing positive TB status reduced women's marital prospects (Liefoghe et al. 1995). In a study in Malawi, where HIV/AIDS is prevalent, patients following treatment and their guardians experienced stigma due to the belief that TB was synonymous with AIDS (Banerjee et al. 2000). In another study across several countries among patients attending TB control programmes, the association of TB with HIV was an indicator of TB stigma in Malawi (Somma et al. 2008).

The above studies, and indeed the majority of studies of TB-related stigma to date, have used in-depth interviews and focus group discussions within a qualitative study design to elicit patient and community perspectives of stigma. These studies have shed light on the different manifestations of stigma among individuals, the community and health professionals, as well as to a limited extent the self-reported affect of stigma on the affected individuals. To increase our understanding of the factors associated with stigma, some authors have suggested building a larger body of literature to include use of quantitative study designs and scales (Kipp et al. 2011; Macq et al. 2006; Zetola et al.

2012), although these are not devoid of complications. There have been few such studies to date (Jaramillo 1999; Westaway et al. 1991) cited in (Kipp et al. 2011) and (Macq et al. 2006)). Some obtain the perspective of TB patients only (Pungrassami et al. 2010); while others compare the patient perspective with that of healthy community members (Kipp 2011), thereby introducing a selection bias. To our knowledge, none has compared the patient perspective with that of a randomised sample of community members. Symptomatic adults in the community are likely to experience higher levels of internal and external stigma, than patients attending TB treatment services who will have overcome many barriers to reach the point of registering for treatment (Kipp et al. 2011; Zetola et al. 2012). Interestingly, there is a possibility that actual stigma may be lower than perceived stigma. In other words, the fear of stigma may be more debilitating than the expression of stigma itself. Few studies (Macq et al. 2006; Somma et al. 2008) have used internally validated stigma scales. Comparison between the various studies is therefore problematic (Kipp et al. 2011; Macq et al. 2006; Zetola et al. 2012).

### *Diagnosis*

Although new tests have become available, the diagnosis of TB in adults in poor populations is mostly achieved through a combination of: clinical assessment; low cost, low technology tests, including smear microscopy; and X-rays. In most settings, a portion of the cost of the consultation and the tests is passed on to the patient, while, once a diagnosis of TB has been made, treatment is free of charge in nearly all public health programmes of LMIC. Treatment for TB was decentralised to the level of health centres, and sometimes lower, to encourage patient adherence and the DOTS was instituted in most countries. The decentralisation of diagnostic services to micro level, however, has not been possible to the same extent as the decentralisation of treatment, since diagnosis requires access to laboratory facilities for the processing and examination of specimens, and the extension of these facilities carries considerable cost implications. In the absence of a low technology test that could be used at the point-of-care, or of a local diagnostic facility, patients are obliged to travel, often some distance from home, and to return on one or more occasions to

provide additional sputum samples. Individuals attending these diagnostic centres may present after a long delay (Cambanis et al. 2005a; Cambanis et al. 2007; Demissie et al. 2002; Sagbakken et al. 2008a; Sanou et al. 2004a; Storla et al. 2008; Yimer et al. 2005), having variously consulted formal and informal health service providers, sometimes at great expense. Patients are often unprepared for the need for multiple visits and a proportion leaves without completing the process, before a diagnosis has been reached (Cuevas et al. 2011a; Cuevas et al. 2011b). The widespread difficulties TB sufferers experience in obtaining a correct diagnosis acts as a major constraint to accessing appropriate treatment (Ramsay et al. 2009).

The majority of TB patients outside the wealthiest nations are diagnosed using direct light smear microscopy, often supplemented by chest radiology. Smear microscopy has traditionally involved the examination of 3 sputum specimens. The first specimen is requested from the patient once TB is suspected (*first on the spot*), the second is collected by the patient on awakening the following morning (*morning specimen*) and brought to the health centre the next day, at which point a third sample is requested (*second on the spot*). This traditional '*spot-morning-spot*' routine requires patients to attend the health centre over 2 or more days, which is cumbersome for patients and their families in both time and expense and might be an important factor contributing to patient drop out from the process. As patients only initiate treatment if they complete the diagnostic process, strategies that facilitate a rapid collection and examination of specimens may result in increased access to treatment (Ramsay et al. 2009).

A revised smear microscopy scheme that avoids the need for patients to systematically return to the health centre the following working day by collecting two on-the-spot sputum specimens on the same day (Cuevas et al. 2011b), was recently endorsed by the World Health Organization (WHO 2011a). This '*frontloaded*', or '*same-day*', scheme identifies an equivalent number of smear-positive patients as the *spot-morning-spot* approach and, if only two smears are used, has the potential to complete specimen collection in a single visit. The '*frontloaded*' scheme may also reduce the costs

incurred by patients by avoiding the second day visit, but services would need the capability to return the results on the same day. While there is an assumption that this approach would reduce the barriers patients face to access diagnosis, this has not been evidenced to date. Studies are therefore needed to assess whether the approach would benefit indigent populations and to establish the changes needed to optimise its implementation in LMIC.

### *Health service delivery*

It is important to locate the study sites within the context of the health systems of their host countries and the general and health characteristics of the population. The table in Appendix 1 shows key health indicators, services and spending figures for general health and TB for Ethiopia, Nepal, Nigeria and Yemen. Nigeria is the most and Yemen the least populous of the four countries. In Nigeria 50% of the population is urban - considerably more than its counterparts which have an urban population of between 17% and 32%. Life expectancy at birth is lowest and the under 5 mortality rate highest in Ethiopia and Nigeria. Rural under 5 mortality rates are markedly higher than urban, although data for Yemen is not available. The proportion of physicians per 10,000 population, an indication of the level of training of the health workforce, ranges from 0.2 in Ethiopia to 4 in Nigeria (with no reported figure for Nepal).

In terms of TB laboratory coverage, the proportion of laboratories with smear microscopy facilities ranges from 0.8 per 100 000 population in Nigeria to 2.3 in Ethiopia. A substantial proportion of notified new TB cases are smear negative and in Ethiopia these exceed smear positive cases. All countries spend approximately 5% of GDP on health; while absolute per capita expenditure on health is by far the lowest in Ethiopia and Nepal. Spending on TB control in absolute terms is highest in Ethiopia and lowest in Nepal.

So far, this literature review has explored the *economic barriers* to attendance at diagnostic services, namely poverty, direct and indirect costs of attendance and economic consequences of rural residency, transportation and distance to diagnostic services, and their association with delayed

attendance. It has also highlighted the particular vulnerability of migrant and refugee populations, in terms of their increased risk of infection and progression to active disease. The chapter has also described the *socio cultural* barriers of gender and social stigma. There are, however, other barriers to attendance identified in the literature that have not yet been alluded to. These fall into the categories of *health system* and, again, *socio cultural* barriers (WHO 2005).

### *Socio cultural barriers*

Many communities lack awareness of the availability and location of TB diagnostic and treatment services, including free treatment and, where offered, free testing (Gilpin et al. 2011; Long et al. 2008; Okeibunor et al. 2006). Knowledge about the disease, its symptoms, methods of transmission, medication and duration of treatment are often partial and incomplete. Many misconceptions and myths prevail as might be expected among the general public, but more surprisingly among TB patients and health professionals. Common misconceptions and beliefs about disease causation include exposure to cold draughts (Armijos et al. 2008; Gebremariam et al. 2011), divine punishment (Baral et al. 2007) and witchcraft (Banerjee et al. 2000; Okeibunor et al. 2006; Sagbakken et al. 2008b). Reported misunderstandings about the means of disease transmission, include using shared dishes, or eating from the same plate (Cambanis et al. 2005a; Gilpin et al. 2011), shared towels or bed linen (Armijos et al. 2008) and supposedly immoral, unhealthy or indulgent behaviours, such as casual sex, visiting prostitutes, drinking alcohol, smoking tobacco or chewing khat (Armijos et al. 2008; Baral et al. 2007; Gebremariam et al. 2011; Weiss et al. 2008). In settings where HIV prevalence is high, the symptoms of TB are confused with those of AIDS (Ngamvithayapong et al. 2000), there is a belief that TB is sexually transmitted (Somma et al. 2008) and the nature of the relationship between TB and HIV is misunderstood (Gebremariam et al. 2011). Misinformation about TB treatment and cure includes treatment through herbal remedies, traditional medicine (Gilpin et al. 2011) and the belief that TB is incurable (Liefoghe et al. 1995). In many countries, people prefer to consult traditional healers, informal healthcare providers or spiritual healers, or to self-treat using traditional remedies, or even to buy over-the-counter drugs at the pharmacy in the

first instance (Eastwood and Hill 2004; Gebremariam et al. 2011; Ngangro et al. 2012; Okeibunor et al. 2006). If symptoms do not improve, the sick person may consult a private practitioner, since in many places private medicine is seen to be superior to public medicine (Khan et al. 2000; Sagbakken et al. 2008b). Many people resort to public health services when they have run out of money, some are referred from the private sector and others attend when the disease is in an advanced state and all other help has failed (Sagbakken et al. 2008a). Some of these choices arise from a desire to conceal the disease, since attendance at a public clinic can lead to gossip or exposure as a TB suspect (Atre et al. 2011; Eastwood and Hill 2004; Sagbakken et al. 2008b). Lack of knowledge and misinformation about TB has been reported to be higher among women (Eastwood and Hill 2004). Men and women have also been reported to display different health seeking behaviours (Johansson et al. 2000). The popular beliefs that a community hold about the nature of health problems, their cause and implications, have been referred to as belonging to the community's 'health culture' and some authors underline the importance for NTPs to understand the prevailing health culture in order to have an impact on the disease (Rubel and Garro 1992).

There are indications that an individual's level of knowledge about TB is linked to their level of education (Armijos et al. 2008; Mushtaq et al. 2010) and by extension that the provision of health education will improve access to TB services and adherence to treatment and modify behaviours that increase the risk of transmission. Nevertheless, some authors warn that the transmission of medical knowledge alone will do little to change social attitudes and health-seeking behaviours, since vulnerable populations often attribute greater importance to economic considerations, socially acceptable behaviour in relation to healthcare decision making and traditional choice of health provider and reducing the likelihood of social rejection (Ngangro et al. 2012; Waisbord 2007).

#### *Health system barriers*

The reputation of TB services, the patient experience and the attitude of health staff have an influence on the acceptability and perceived accessibility of services by the community. Demands

for extra payments, overcharging, diversion of public funds, differential treatment of patients according to their financial means and staff absence for private work (Okeibunor et al. 2006; Sagbakken et al. 2008b), where present may combine to make the patient's experience at the clinic a negative one, to erode public trust and to earn the clinic, and public health services in general, a bad name. These negative experiences contribute to the patient default rate and result in delay or non attendance by symptomatic adults from those communities in the future. In many settings, mistrust of the TB control programme is a key barrier to accessing TB diagnosis and government clinics are stigmatised as institutions for the poor (Sagbakken et al. 2008a). In China, for example, TB suspects were sceptical about the concept of free diagnostic and treatment services provided by the government, since some had learnt from hearsay that only part of the service was free, others were disbelieving that the government would provide anything for free and some felt that free drugs would be of poor quality (Long et al. 2008). As previously mentioned, free treatment covers a fraction of the total cost of TB care to patients (Wei et al. 2009). Poor communication and transmission of health information between health professionals and their patients also has an adverse impact on the accessibility of services (Hane et al. 2007; Sagbakken et al. 2008b).

Attempts to decentralise health services have often had more success at primary level, than at the level of specialisms such as TB, since specialist services are often weakened by decentralisation (WHO 2005). There is a risk that decentralisation will result in a loss of service quality particularly in remote, rural areas and poor urban settlements (WHO 2005). The tendency for diagnostic services to be centralised and located in urban centres, means that rural and remote populations are disadvantaged, since public transport is often not well developed, terrain can be difficult and mountainous, and distances to urban centres considerable (Cambanis et al. 2005a). Nomadic groups such as pastoralist communities (Gele et al. 2009) and migrants are also vulnerable, since NTPs have not been developed with the flexibility to serve these mobile populations (Deng et al. 2006; Hussen et al. 2012; Long et al. 2008).

## **Conclusion**

A review of the literature has shown TB to be predominantly a disease of poverty and inequity. Many symptomatic adults do not consult formal diagnostic services or consult late at considerable personal cost in time, expense and health. This is both a result of the lack of accessible health systems and a multitude of factors that obstruct attendance, including most importantly financial, social and educational deprivation, as well as social stigma. Of those adults that attend diagnostic services, many drop out, some are incorrectly diagnosed as not having TB and a proportion of those that are diagnosed with TB do not register or complete treatment. There appear to be many similarities between the barriers to accessing TB services at each stage ('help-seeking', diagnosis and treatment); however, since the studies employ differing study designs in widely differing health, country and geographical contexts, comparisons are difficult. Individual barriers will have differing degrees of prominence at each stage. For example, treatment services are likely to be available at a more local level than diagnostic services; however the gain in convenience is offset by the longer duration of the treatment phase. Few studies describe the experiences of patients during attendance at TB diagnostic services.

There is an interplay and interconnection between the different barriers. For example, adults living in poverty are likely to have a lower educational level, less knowledge and awareness of TB and health services, to use traditional, informal and private medicine, to experience and promulgate the social stigma surrounding the disease and to have less access to healthcare. Many symptomatic adults will face one or two barriers to obtaining appropriate care and some may have the economic and social resources to overcome these. The most vulnerable and disadvantaged, however, are likely to experience several barriers, as well as having fewer emotional, economic and social reserves to overcome them. It is when multiple barriers are experienced by the most vulnerable populations that achievement of care and treatment is less attainable.

## **Chapter 3**

### **Methodology**

#### **Introduction**

This chapter describes the background to the set of studies, the general organisation, study design and methodological issues pertaining to more than one study. For the most part, the methods for individual studies are described in specific chapters to facilitate interpretation of the results. This approach was considered to allow a better understanding of the studies, as a combined description of quantitative and qualitative methods would have led to repetitive reference to each study. This chapter therefore provides an overview of the research and is the foundation for the study specific methods sections of chapters 4 to 7.

#### **Background and general organisation of the studies**

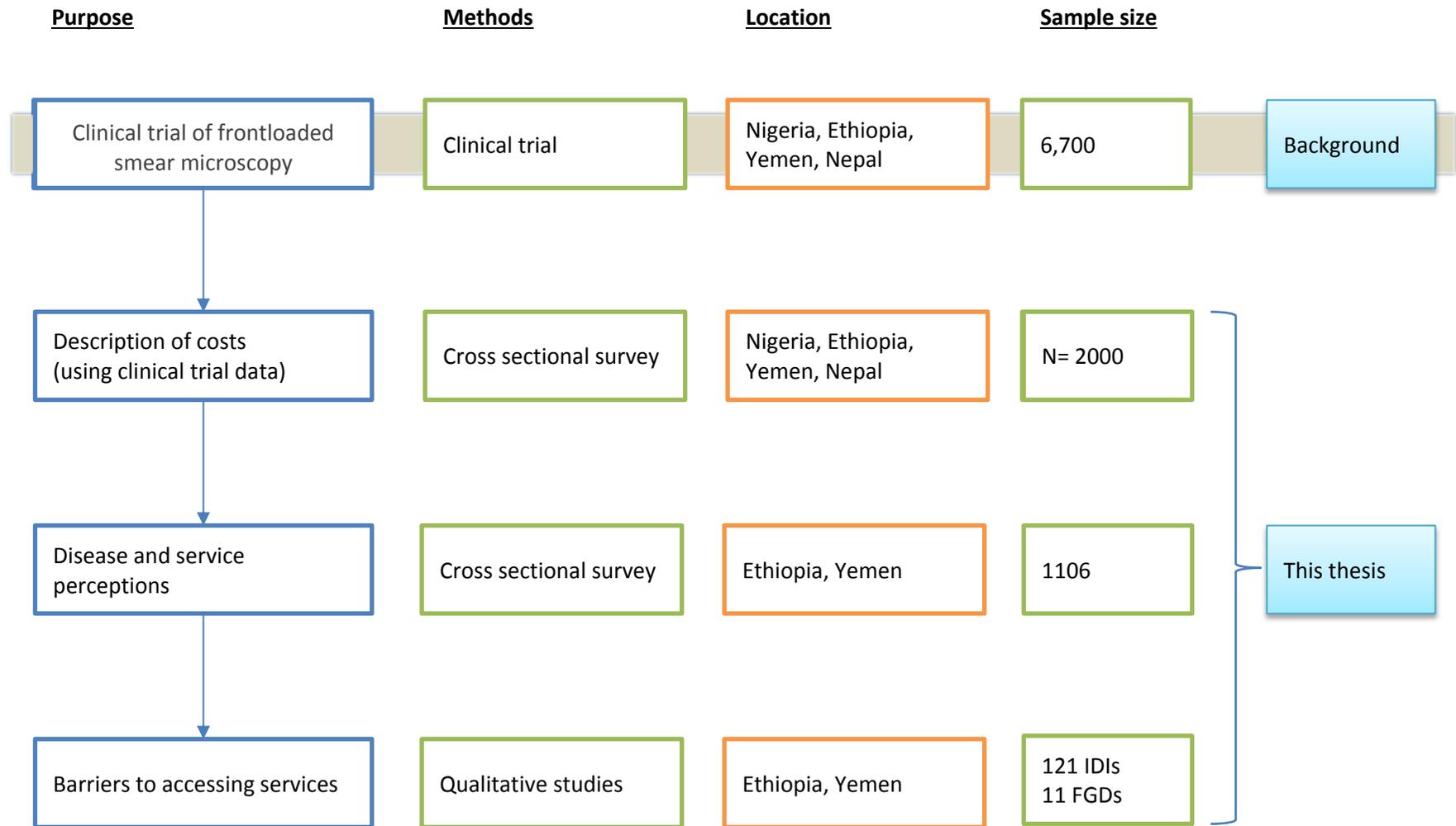
This study is related, in part, to a multi-centre study led by Prof. Luis E Cuevas to demonstrate that an accelerated, or 'frontloaded', diagnostic scheme using smear microscopy had similar sensitivity and specificity to the standard scheme, which had been followed for the last 50 years in most countries. The study started in January 2008 and adult patients with chronic cough attending selected diagnostic centres in four countries were enrolled to demonstrate that the new scheme was not inferior to the standard scheme. Patients were randomised by week for examination by direct sputum smear microscopy under the *standard* scheme for collection of specimens or the *frontloaded* (also called *same-day*) scheme. The standard scheme collected the first sputum specimen on the spot, at the time of the patient's first consultation, a second specimen was collected on the morning of the next day (called the *morning* specimen) and a third specimen was collected on-the-spot, on the second day of consultation. The frontloaded scheme collected specimens in a slightly different order, obtaining two specimens on the spot on the first day of consultation (i.e. spot-spot) and a third specimen on the morning of the second day (thus called spot-spot-morning). The rationale for this approach is that most patients with positive smear

microscopy are identified by the first two specimens and that collecting the two specimens on the first day would identify most smear-positive patients on the first day of consultation. In addition, the WHO had revised its guidelines for smear microscopy and had recommended examination of two smears instead of three (WHO 2007b), therefore most patients using the frontloaded scheme could be examined with the specimens submitted on the first day of consultation. The recruitment and diagnostic pathway for study participants is shown in Appendix 2.

The study was planned as a non-inferiority clinical trial and aimed to assess whether the frontloaded scheme had comparable sensitivity and specificity to the standard scheme for the diagnosis of Pulmonary Tuberculosis (PTB). A total of 6,700 patients were enrolled in Ethiopia, Nepal, Nigeria and Yemen and the main results were published in 2011 (Cuevas et al. 2011a; Cuevas et al. 2011b). Each study site had a partner coordinator and field activities were conducted adopting the same protocol across all sites. Since the frontloaded scheme had the potential to reduce the number of clinic visits and by extension the patient default rate, the study also compared the degree of patient compliance.

This thesis was developed alongside the WHO-funded study to ascertain the cost of diagnosis for most patients, the acceptability of the scheme and potential savings made by not attending on the second day, based on an analysis of survey data gathered during the clinical trial. The doctoral studies extended the clinical trial with supplementary studies to ascertain patients' knowledge of the disease, perception of diagnostic services and barriers to accessing diagnosis, as described in Figure 3.1, but did not attempt to compare the two schemes. Most of the additional studies were funded by a joint research programme of the ESRC and the then DFID, currently called UKAID. Although the studies were intended to run in tandem, they ran in succession due to a 3-month delay in approval of the budget.

Figure 3.1 Diagram outlining the studies conducted for this thesis in the context of a larger clinical trial.



This thesis therefore reported a cross sectional survey to describe patients' costs conducted in Nigeria, Ethiopia, Yemen and Nepal, which was a small component of the WHO-funded clinical trial. The PhD candidate managed and analysed the cost data, but did not contribute to the design of this study. The main body of the thesis comprised a second cross sectional survey conducted six months later to identify non-financial issues that could generate barriers to accessing diagnostic services in Ethiopia and Yemen and complement the information obtained in the first survey. The surveys were complemented by qualitative studies with patients in the same settings, which allowed a more detailed exploration of the issues raised in the quantitative studies and sought explanations for some unanswered questions. In depth interviews (IDIs) and focus group discussions (FGDs) were used to elucidate, confirm, expand and illustrate survey responses through patients' stories in their own words. This study phase was also used to explore with patients the changes that could be made to health service delivery to facilitate patients' completion of the diagnostic process. The qualitative study is one of the few to use a single protocol to compare the problems of access, as well as the factors that enable diagnostic completion, as experienced by patients across two study settings. Quantitative and qualitative studies discussed the differences and commonalities in the patient experience in the different settings and considered how these might be relevant or applicable to other contexts. The patients' sociodemographic characteristics, health seeking behaviour prior to attendance, attitude towards and knowledge of TB, perception of service quality and access to social support networks were described; all of which are known to influence patients' access to healthcare and the probability of a successful outcome.

### *Epistemological framework*

This study is informed by two research paradigms - positivism and naturalism - since it lies at the intersection of two academic disciplines, the biomedical and the social. This led to a decision to adopt a mixed methods approach, using quantitative and qualitative research methodologies and different research tools within these. The use of multiple methods was felt to be particularly appropriate due to the ability of surveys to quantify costs and establish the prevalence of beliefs and

the main issues to be explored in subsequent qualitative studies. The quantitative phase was designed to capture the way in which large numbers of patients responded to and experienced the standard and accelerated diagnostic schemes in relation to their adherence to the scheme, the costs they incurred, time involved and the social impact of attending services. The study thus began with the quantitative studies in order to obtain a broad overview of the issues before exploring them in more depth in the qualitative phase. The qualitative phase aimed to capture the reasons for patients' behaviour and the meaning that patients attributed to their experiences of healthcare.

*Survey to describe patient costs:*

This study was conducted in parallel with the clinical trial. In addition to collecting information for the main outcomes of the clinical trial, data were collected from the first 500 patients with chronic cough attending each centre to assess the direct costs incurred by patients attending diagnostic services. Information was collected using questionnaires with closed and multiple choice questions and patients were interviewed on the first day of attendance (Appendix 5). This cross sectional study component had the purpose of generating knowledge about patients' expenditure; identifying groups that had higher diagnostic costs than the majority of participants and exploring the impact of the cost of attendance on typically poor, marginalized and underserved populations. This study is described in chapter 4.

*Survey to describe patients' perception of the disease and services:*

This cross sectional survey aimed to describe patients' perception of diagnostic services, their understanding and misconceptions about the disease, manifestations of social stigma, perceived barriers to accessing services and accuracy of the diagnosis. The study aimed to provide preliminary data to inform the qualitative studies planned (described below), and was conducted some six months after the initial cost surveys. The study was intended to be implemented in Yemen, Ethiopia and Nepal; however, due to political unrest in Nepal, the study was only implemented in Ethiopia and Yemen. After the period of training and standardisation of study procedures, the field studies

started with quantitative data collection in February and March 2009 in Yemen and Ethiopia, respectively. Social scientists and social workers were specifically employed to conduct the surveys in each country, study field coordinators from both countries attended a workshop at LSTM to inform the protocol and the development of questionnaires and the PhD research student travelled to Sana'a and Hawassa to oversee their implementation in the field. Questionnaires utilised a mixture of standard, closed questions and 2 types of multiple choice question. One required the enumerator to check off the answer(s) mentioned by the patient against a list of possible answers and in the other, the enumerator read out the choice of responses to the participant (Appendix 6). Acceptability of services was measured using Likert scales that ranged from very negative to very positive perceptions. The findings of the surveys in both countries are presented jointly in chapter 5.

#### *Qualitative studies in Yemen and Ethiopia:*

Quantitative studies were followed by qualitative studies to complement and triangulate the findings of the two surveys. Qualitative studies comprised IDIs and FGDs with patients in Ethiopia and Yemen (Appendices 5 and 6). Study coordinators received training in qualitative methods in Liverpool in the autumn and spring of 2008-9, and the PhD research student travelled to the countries to facilitate initiation of the studies. Interviews were recorded and transcribed in the local languages, and translated into English by professional translators. Translations were checked by the study coordinators for quality control and re-translated as necessary. Field coordinators double translated selected transcripts for comparison with the translator's version to check for accuracy and authenticity. The findings of these studies are presented separately for each country in chapters 6 and 7.

#### *Location of the studies*

The participating centres were selected at the time of the clinical trial, because they had a high turnover of patients, belonged to the NTPs, were mostly providing services to populations with limited financial resources and had established collaborative links with LSTM. The study sites for the

original clinical trial comprised centres in Yemen, Ethiopia, Nepal and Nigeria; which are countries with a high incidence of TB. Although the first cost survey was conducted in all 4 countries, Nigeria was not included in the remaining studies due to funding constraints. In addition, following difficulties encountered in implementing the study in Nepal (see study limitations), and in consultation with the funding body, the study was further restricted to the Ethiopian and Yemeni sites.

The Tuberculosis programmes in the host countries had adopted and implemented the DOTS strategy as recommended by WHO. Although the private sector is a major healthcare provider in all four countries, the control programmes were delivered exclusively through government health facilities, namely hospitals, health centres and health stations. The NTPs operated a passive case finding strategy, providing diagnostic services from fixed health posts. TB treatment was provided for free, but charging policies during diagnosis varied between and within countries.

#### *Partner institutions*

The partner institutions were:

In Ethiopia: Bushullo Major and Awassa Health Centres in Hawassa (frequently spelled Awassa), in the Southern Region. Bushullo Major Health Centre is a missionary hospital situated just outside Hawassa and treats approximately 260 patients with chronic cough per month, of whom 60 are confirmed to have TB. Hawassa Health Centre is the main ambulatory health centre of the city. Dedicated staff was employed at each health centre to carry out interviews. The interviewer in Awassa Health Centre was a nurse and was studying for a degree in social sciences. The interviewer in Bushullo was also a trained nurse and had participated in previous studies on social medicine; tracing defaulters and discussing reasons for defaulting. A further 2 nurses joined the study after the first 6 months; one of whom had long term experience working on TB in the community.

In Yemen: studies were conducted in the National Tuberculosis Institute (NTI) in Sana'a, Yemen. This government referral centre attends approximately 800 patients with respiratory problems and 120

cases of TB per month. Three interviewers were employed for both the quantitative and quantitative phases. Interviewers for the cost survey were trained in pharmacology, general health studies and nursing respectively. The staff employed for the second survey and qualitative phase had a degree in social sciences, programme experience and one was a lecturer in the School of Sociology at Sana'a University.

In Nepal: survey participants were enrolled from the DOTS Centre at Tribhuvan University Teaching Hospital and from the Dirgh Jeevan Health Care and Research Centre, Kathmandu. The former is a health centre dedicated to the diagnosis and treatment of TB and is part of the NTP, providing diagnosis and treatment free of charge to about 300 patients per month. The second is a busy, low-cost, private clinic specialising in chronic respiratory infections. The latter was included to augment the number of study participants and to obtain a wider representation of patients, as many patients in Nepal prefer to attend a specialist clinic for diagnosis and are subsequently treated by the private clinic or referred to the DOTS centre.

In Nigeria: patients were enrolled in Wuse District Hospital in the Federal Capital Territory of Abuja, Nigeria. Wuse is a busy government District hospital. Patients attending the centre receive diagnostic and treatment services for TB free of charge, but the hospital did not have a laboratory service at the time of the study. For this reason sputum specimens were processed in Zankli Medical Centre (ZMC) TB Research Laboratory. ZMC is a private, for-profit hospital in Abuja which has developed the TB research laboratory for philanthropic reasons and to promote research in Government services. Over the years, the centre has participated in many research studies and was endorsed as a diagnostic centre through a contractual arrangement with the NTP. The laboratory acted as the main laboratory for the recently completed WHO National TB survey and the national MDR survey sponsored by the US Centers for Disease Control (CDC).

Three of the study sites were thus located in capital cities, with the exception of Bushullo Major and Hawassa Health Centres in Ethiopia. The NTI in Sana'a, the University Teaching Hospital in

Kathmandu and Wuse District Hospital in Abuja, attract patients from the locality and nationally, although the reputation of Bushullo Major Health Centre is such that patients also attend from large geographical area. The implications of the differences in the study sites for the findings are taken up in the Discussion chapter.

### **Study coordination**

The clinical trial was led by LSTM staff and WHO/TDR in collaboration with staff at the health centres belonging to the National Control Programmes in the partner countries. For the studies reported in this thesis, a partner coordinator (who in most cases had also coordinated the WHO/TDR studies), a social scientist and social worker(s) were specifically employed for the research in each study site. Field activities were conducted adopting the same protocol and approach across the study sites, with small modifications for the qualitative studies to accommodate cultural sensitivities. Study field coordinators from all four countries attended a protocol development workshop for the costs study and staff from Ethiopia and Yemen attended a workshop at LSTM to inform the final protocol and development of study questionnaires for the second survey. Study coordinators received training in qualitative methods in the autumn and spring terms of 2008-9.

### **Study participants and approach**

#### *Survey to assess diagnostic costs in Yemen, Ethiopia, Nigeria and Nepal*

These surveys were conducted with adults above 18 years of age with a history of cough of  $\geq 2$  weeks' duration. Patients were invited to participate at the time of their first attendance. Information was gathered to ascertain the patients' socio-economic background and risk factors for defaulting from the diagnostic process or treatment registration. At least 500 patients were enrolled consecutively from each site and interviewed face to face using a structured questionnaire that included some open, but mostly closed questions (Appendix 5). All interviews took place on the first day of attendance, therefore the costs of attending for a second day was estimated by patients. Participating health centres were instructed to alternate the standard (spot-morning-spot) and

frontloaded (spot-spot-morning) schemes according to a predefined timetable that was coordinated across the study sites and was concurrent with the clinical trial. After registration with the health centre, patients attended a first consultation with the centre staff. If the clinician suspected TB, the patient was sent for smear microscopy and his/her details entered into a logbook. The first six patients referred for smear microscopy per day (30 per week) were selected for interview. Some flexibility was allowed due to fluctuating patient numbers, as in Ethiopia for example the clinic was less busy on market day and on Fridays for the Muslim call to prayer, and busier after the weekend break. Interviews were held before patients received health education.

#### *Survey to assess perception of services and understanding of the disease*

The second study was conducted 6 months later. This study enrolled patients with the same entry criteria. Patients were selected consecutively and interviews were held by the study staff and lasted approximately 30 minutes. Patients completing smear microscopy were invited to attend a follow-up interview, which for the majority took place on the second day of attendance (Appendix 6). This second interview took place after patients had consulted the clinician and their laboratory results had been discussed.

The quantitative studies were used as a framework to identify participants for the qualitative studies. Data routinely collected by the centres was used to monitor adherence to the standard and frontloaded diagnostic schemes, the proportion of patients who initiated treatment and treatment completion rates. An additional monitoring system was established to record and trace patients with cough  $\geq 2$  weeks' duration, suspected of having TB, attending the centre over a period of 18 months.

Patients that agreed to participate were allocated a study number and identified by placing a sticker on sputum specimen bottles and laboratory results. A separate logbook was held in the laboratory for patients participating in the quantitative phase. This logbook included basic demographic information, contact details, cough duration, smear microscopy scheme and results and recorded

whether patients had completed smear microscopy in order to ascertain the proportion of patients who dropped out of the process. Health workers then attempted to contact defaulting patients to establish a brief reason for dropping out.

Smear positive patients were followed to ascertain treatment registration. Patients with TB are routinely referred to treatment centres designated by the TB Programme, where they register for treatment. The proportion of smear positive patients registering for treatment was monitored by recording the patient's preferred treatment centre at the time of diagnosis and the number of patients initiating treatment was monitored by contacting the treatment centres 2 weeks and 1 month after referral. If a patient had not registered, other treatment centres serving the patient's local area were contacted to ascertain whether the patient had registered in another centre. Checks were made by telephone or in person. If no record of the patient was found, an attempt was made to contact the patient by telephone or home visits to ascertain whether they had registered for treatment and if not, establishing a brief reason why. As the intention of this surveillance system was to monitor treatment registration rates and allow identification of participants for the qualitative studies, these data are not reported unless they provided information for the qualitative studies in chapters 6 and 7.

#### *Qualitative studies*

These included in depth interviews (Appendix 7), focus group discussions (Appendix 8) and case studies to provide an insight into patients' perception of services, processes leading to patients abandoning the diagnostic process or failing to register for treatment and barriers and supportive factors for completion and adherence.

Participants in the IDIs were individuals who abandoned or had completed the diagnostic process and initiated or did not initiate treatment. Individuals who had *completed* the diagnostic process included patients with positive and negative smear-microscopy. Interviews with patients who completed and defaulted from diagnosis aimed to explore ways services could be modified to

facilitate access, patients' experience of the diagnostic process, and to identify barriers and enablers for diagnostic adherence. Interviews with defaulters aimed to confirm the information collected in the surveys as a basis for discussing the reasons why the person had abandoned the process. A similar interview format was employed with both groups. Interviews conducted with individuals both registering and not registering for anti-TB treatment explored patients' perception of treatment access and identified barriers and enablers for treatment adherence using a similar interview format. Participants were identified through the surveillance system described above and additional patients who had not completed the diagnosis were identified in the centres' register. Patients were contacted by telephone or home visits to arrange appointments. Interviews took place in discrete locations in the health centre, at the patients' home or at a mutually convenient setting, as arranged with the participants and these locations are described in more details in the respective results chapters. Purposive sampling (Patton 1990) was used to ensure inclusion of younger and older participants of both sexes, of different socio-economic status, ethnicity and geographical location. Interviews were conducted until the newly enrolled participants ceased to provide fresh information. It was expected that information saturation (Strauss and Corbin 1990) would be obtained with a minimum of 25 interviews of 30 to 60 minutes duration in each site.

Participants in the FGDs were patients that completed the diagnostic process and initiated treatment. FGDs were conducted for data triangulation (Bryman 2008), experience sharing, prioritisation of needs and exploration of group norms and dynamics and their impact on treatment seeking. It was expected that a minimum of 2 FGDs per selection category would be required to obtain information saturation. Discussions were held at suitable locations convenient to the patients and these varied by study location, as described in the respective results chapters. Patients were grouped geographically as much as feasible. Travel expenses were reimbursed and refreshments were provided for patients and accompanying relatives. Although the risk of cross infection between patients was minimal (as patients had initiated treatment several weeks earlier),

care was taken to reduce the risk by gathering in a well-ventilated area or in the open air, with exposure to sunlight, as recommended for DOTS programmes.

### *Training and piloting*

A period of training with field staff and piloting of research tools preceded the launch of the quantitative and qualitative phases of the study in each site. Following development of the study protocol and research tools, and approval by the LSTM Research Ethical Committee Appendix 9), the PhD research student undertook familiarisation visits to Yemen, Nepal and Ethiopia between August and October 2008 and helped to interview social scientists and social workers to assist the local coordinator and PhD research student with data collection. The PhD research student was accompanied by one LSTM investigator in Yemen and Nepal and a second investigator in Ethiopia. The student used the visits to become familiar with the TB control programmes, meet local partners and programme staff, learn about the cultural, social and religious contexts, and discuss approaches to data collection and surveillance. Quantitative research tools were pre-tested and the PhD research student contributed to the monitoring of the study to validate the accelerated diagnostic scheme and the survey on costs.

Structured questionnaires for the cross-sectional surveys were tested together with the local coordinator with health centre staff and patients. A note was made of the cultural acceptability of questions, the duration of the interviews, difficulties in translation, wording ambiguities and problems with the flow of the questions. The questionnaires were then amended in discussion with the research steering group. The questionnaires were uniform across study sites, with the exception of a question about HIV testing and status, which was not considered acceptable in Yemen.

Further on-site training was provided by the local field coordinator, the PhD research student, the principal investigator and other members of the steering group, as informed by the study workshop and training in qualitative research methods at LSTM. Local enumerators, laboratory staff and clinicians were trained in screening, recording, laboratory and monitoring procedures.

The field coordinator and co-investigator from Yemen came to Hawassa to share their experiences of initiating the qualitative phase of the study in Sana'a, to learn about the context specific to Hawassa and support the team to run training for qualitative data collection. A member of staff from LSTM with expertise in qualitative research accompanied them to oversee the training and the launch of the study. The experiences, data and language emerging from the quantitative phase informed the development of qualitative research tools.

#### *Tracing and locating patients*

A pilot study was conducted in Hawassa Health centre to assess the feasibility of contacting patients using mobile phones. Only about 1 in 10 phone numbers were routinely recorded and it took 1 hour to test 6 phone numbers, of which 4 were valid. The co-investigator for Ethiopia reported that patients who answered were happy to be contacted and were pleased the health centre was interested in their welfare. Interviewers were trained to record more detailed, descriptive addresses to trace patients without a phone, as locating addresses was deemed to be time consuming and often required going through the kebele chairman. The number of patients declining to participate in the studies was recorded, including date of refusal, gender and interview type. The refusal rate and profile of patients declining to participate was monitored to ensure that no selection bias had been introduced into the study.

#### **Trustworthiness, validity and limitations**

##### *Effects of research*

Every effort was made to ensure that the research did not delay or otherwise influence health care. On average, a maximum of 6 patients per day were recruited at each site for the survey interviews to maintain interview quality and to avoid obstructing the patient flow in the health centres. Interviewers were trained not to give health care or health information as part of the research interview. Instead, interviewers referred patients' questions to the appropriate member of health staff at the end of the interview. Health workers were trained not to pressurise patients and risk

altering their behaviour. When tracing patients referred for treatment, health workers first telephoned treatment centres and only contacted the patient directly as a last resort. Health information was provided at the end of the FGDs by the health education officer from the NTP in the form of a presentation and/or leaflets to rectify any misleading information or misconceptions shared or held by group participants.

Patient adherence had been seen to improve during the clinical trial study in Sana'a (personal communication by partner coordinator). It was assumed that this was due to patients receiving increased attention, explanation and follow-up from health or research staff than during routine care. This appears to have been true for the current study, in which the default rate from diagnosis was lower than usual, with only a few patients failing to return on the second day. Moreover, none of the patients referred for treatment with smear positive TB failed to register at a treatment centre in Sana'a, with the exception of patients who had died. Although statistics before the studies are unreliable, 3 staff members independently estimated the proportion of patients failing to register for treatment outside study conditions (including patients with a clinical diagnosis) to be at least 3%.

#### *Language issues*

Research instruments were translated into the national (or main local) language: namely Amharic in Ethiopia, Nepalese in Nepal, Hausa in Nigeria and Arabic in Yemen. Where research participants spoke another local language, a translator was identified who could provide simultaneous translation. This was often the person accompanying the patient. Language however became an important issue to timely monitor information saturation. As interviews took place in a large number of languages and the process of translation into English was time consuming, interviews took place at a much faster pace than translation. It was therefore not possible to decide whether information saturation had been reached by the teams. This issue led to the number of IDIs and FGDs being unusually large. After discussion with the PhD supervisors, it was decided that it would

have been unethical not to include all transcripts in the analysis, which resulted in an unusually large number of transcripts.

It was also interesting how disempowered the PhD research student felt not being able to speak or understand the language, read the script or, in Yemen, even the numbers. Again, this affects the manner in which the fieldwork is conducted and reinforces the disparity between the methodological ideal conceived from the researcher's office and what is feasible on the ground.

### *Employment issues*

As in many developing countries, work positions can be fairly insecure in Nepal, Yemen and Ethiopia, and not well protected by employment law. Salaries are low and it is common to have more than one job, which affected the availability of project staff. Employees may leave for another position which offers a more attractive salary. The staff employed for the research study in Ethiopia remained fairly constant throughout the project, as salaries were competitive with local salaries and due to the loyalty of staff to the project. Introducing higher salaries as part of a research project causes difficulties of its own, however, such as resentment by other staff, as there is often a strong sense of the importance of respecting professional hierarchies. In Nepal, the change of government in August 2008 brought changes in senior personnel in the university and department of health and the future of the project became uncertain.

The staffing situation in Sana'a was possibly the least stable. Despite a careful selection process, there was a high turnover of staff employed for the research study in Yemen. In order to minimise the effects of discontinuity of staff, the steering group invested in training the co-investigator and local co-ordinator, which had worked with LSTM over a period of 10 years. This provided a more durable solution, as they were able to train new team members. The research personnel were employed in accordance with cultural norms. In Sana'a a woman does not traditionally travel alone or with a man outside her immediate family, and when travelling with a female companion, does not travel far from home. It was therefore necessary to employ one male social scientist and two

female social workers. In this way the team was able to interview patients of both sexes, either in the clinic or in the community. When interviewing outside the clinic, the 3 interviewers travelled together in order to cover any eventualities, such as a male being present in the household of a female patient. This arrangement was of course costly in terms of resources including salaries, travel, work time and other expenses.

#### *Change of government in Nepal*

A visit to the study site in Kathmandu, Nepal, in August 2008 revealed that there was a rapidly changing political climate and the newly elected government had appointed new administrative staff in the Institute. The study partners in Nepal felt it was not a suitable time to initiate the study and after consultation with the funding body, permission was obtained to drop the field location.

#### *Culture, customs and religious sensitivities*

In Yemen, research and health staff informed the steering group that HIV/AIDS are not spoken about. Rates of infection are presumed to be low (as is the practice and uptake of HIV testing) and it is considered an affront on someone's honour and moral integrity to ask their HIV status. It was therefore not possible to ask the majority of patients about their understanding of the link between HIV status and susceptibility to TB. This question was directed to Ethiopian and Somali patients only, who are routinely tested for HIV on entering the country. Contrastingly, in Ethiopia, public awareness of HIV/AIDS is fairly good and with the availability of anti-retroviral treatment, acceptance of voluntary counselling and testing is also relatively high. It was therefore acceptable to ask patients whether they had been tested.

Due to tensions between a branch of Shia Islam seeking greater autonomy in the north of Yemen and the government, local partners considered it to be too sensitive to ask patients about their religious denomination or affiliation. Instead, a general question was asked and patients were able to choose whether or not to specify denomination or affiliation.

Individual interviews were difficult to obtain in some contexts. This was particularly true in Sana'a, where Yemenis travel in groups and it is rare for a patient – whether male or female - to attend the clinic alone. Most are accompanied by one or more family members or friends. Obtaining the unique perspective of the patient was therefore problematic, as a more senior person or male accompanying a female patient would tend to answer on behalf of the patient. Even without gender or age differences, it is commonplace to join in a discussion and to add one's point of view. Exploring the issue of a woman's freedom to seek healthcare was particularly problematic, as women are generally accompanied by a man and are unlikely to be able to answer the question freely. Patients were also reluctant to be separated from the family members or friend(s) accompanying them, or to go with their companion(s) into an adjacent room where the interview would be more private. The researchers decided therefore to take this into consideration when interpreting and presenting the data: to note that the viewpoints expressed were likely to be the perspective of the patient and his/her companions. Of course, there was concern that not being able to interview the patient alone would compromise patient confidentiality and the validity of responses, especially regarding sensitive topics. In the planning phase, holding an FGD for women alone was considered problematic. An all-female group discussion took place, however, facilitated by female research staff. Men and children accompanying the female research participants were invited into an adjacent room by male research staff when the discussion started and were provided with refreshments. In Ethiopia, on the other hand, although patients are usually accompanied to the health centre, they for the most part attended the interview alone.

### *Stigma surrounding TB*

In addition to the fact that few patients in Awassa, Ethiopia, had a phone, project staff reported some reluctance among patients to provide a phone number, due to fear of family members or friends finding out their TB status. These issues are explored in more detail in the qualitative studies.

### *Group confidentiality and implicit disclosure*

There was a danger that attendance at FGDs would indicate that participants' had a positive TB status. This was not felt to be problematic for those FGDs held with patients that had been referred for treatment and were therefore all TB positive, but more so for mixed groups, comprising patients who were TB positive and negative who had presented for diagnosis. Where this was the case, participants were clearly informed that disclosure to the group was voluntary and the need to respect the confidentiality of group members was underlined. At the same time, researchers made it clear that confidentiality from other research participants could not be guaranteed.

### **General comments on methods**

The eligibility criteria for diagnostic investigation outside the conditions of this study varied from country to country. This is in part due to differences in the function of the healthcare facilities in each of the study sites. In Hawassa and Kathmandu, the facilities screen patients presenting for general health problems, while in Sana'a the centre sees patients with respiratory problems or suspected TB only. As a result, the site in Sana'a is very compact. This necessitated different approaches for the enrolment of patients across the study sites and the organisation of data collection.

While Yemen, Nepal and Ethiopia share many common barriers to access to healthcare for TB, each has unique circumstances resulting from the differences in infrastructure, culture and social framework. Barriers for women appeared particularly acute in Yemen and considerable in Ethiopia. The approach to work is also contrasting. In Sana'a, the atmosphere in the TB centre is noisy, participatory and rushed, while in Nepal and Ethiopia the approach is calmer, apparently more meticulous and considered. Public acceptance of HIV/AIDS appeared highest in Ethiopia and lowest in Yemen. A factor common to all 3 countries, is that barriers to diagnosis and treatment can be very simple and practical; for example having no sign for the temporary DOTS clinic, no clean drinking water and a patient not having a plastic bag to carry medication.

## **Ethical considerations**

The protocols received approval by LSTM research ethics committee in 2008, followed by local approvals in Nigeria, Nepal, Yemen and Ethiopia research ethics committees, as appropriate. The cost study had been included in the clinical trial protocol and thus was also approved by the WHO Institutional Review Board. The second quantitative survey and the qualitative studies were approved by ethics committees at LSTM, Tribuhvan University, University of Hawassa and Sana'a University. The researchers were aware of the stigmas surrounding TB and the sensitivities implicit in the disclosure of TB status and invited participants in a culturally appropriate manner. All participants were informed of the purpose of the studies and only enrolled if the patient had agreed to participate.

## **Sample size for the surveys**

Sample size for the quantitative survey was calculated using a very conservative approach, because there was limited information on the prevalence of the characteristics of the participants and it was expected that these would vary between study settings. Given that the centres were able to enrol large numbers of patients and that staff solely dedicated to the studies was available, it was decided to select a minimum of 462 patients per study site. This number would be able to establish the prevalence of the characteristics of the participants with confidence limits of 5% even when the expected frequency of the characteristic is 50% (the prevalence that requires sample size). However, it was decided to enrol 500 patients, as this target size was easier to explain to all sites and to allow the replacement of participants who later were found not to comply with the enrolment criteria.

## **Framework for data management and analysis**

### *Quantitative phase*

Data obtained using questionnaires were entered in Ethiopia and Yemen. Once data entry had been completed, a preliminary data cleaning routine was conducted by preparing frequencies and identifying outliers and unusual distributions. Questionnaires were then shipped to LSTM and a

more formal data cleaning process took place by checking paper questionnaires against the electronic databases. Quantitative data was analysed using Epi-Info employing standard statistical methods including summary statistics and confidence intervals. Descriptive statistics were prepared for each variable. These included means (SD) for continuous data with normal distributions, medians (inter-quartile range) for skewed data and frequencies and percentages for discrete and categorical variables. Comparisons of the characteristics of the participants in each country were tested using parametric statistics. A note was made of the N (%) of data missing for each variable. The percentage given for each variable is the valid percentage, taking into account missing data.

The costs for patients were summarised as the mean/median costs for each day of attendance and the mean/median total cost of diagnosis for patients in each country was compared using parametric/non parametric tests. The local currencies of the study sites were converted to US dollars using mid-market rates (XE 2010). A more detailed description of the cost analysis is included in chapter 4.

In order to provide an indication of the level of poverty within each country, 2 key measures of poverty were used: the Multidimensional Poverty Index (MPI) estimate H and income poverty calculated as the proportion of people living on less than \$1.25 per day. The Multidimensional Poverty Index was developed by the Oxford Poverty and Human Development Initiative (OPHI) and is designed to capture the impact of and interaction between multiple deprivations that affect household members individually and collectively. It uses 10 indicators of poverty within the dimensions of education, health and standard of living. H refers to the headcount, or incidence of multi-dimensional poverty within the country's population. These measures of poverty have been shown to yield very different results and both were provided to allow for comparison.

#### *Qualitative phase*

The analysis followed the Thematic Analysis method, as described by Braun and Clark (Braun and Clarke 2006) and drew on the Framework Analytic method, as conceived by Ritchie and Spencer

(Ritchie and Spencer 1994). The researcher adopted a 'contextualist' approach to the analytic process; that is to say one that lies between the essentialist and constructionist traditions (Braun and Clarke 2006). The PhD research student does not subscribe to a purely realist approach, but recognises that the researcher is an active player in the analysis. In other words, the identification and classification of text and themes, choice of what is relevant, the way data is synthesised, theorised, framed and presented, are not neutral acts and will change the final interpretation of the data (Braun and Clarke 2006). For the same reason, the research team occupied the middle ground between an inductive and theoretical thematic analysis (Braun and Clarke 2006), recognising that they arrived at the analysis with specific questions and themes informed by knowledge of the subject area, the surveys and reading of the literature, but took care not to impose these theories on the data. The IDI and FGD guides were semi-structured and required interpretation of the data produced. Patients' responses were mediated by power and hierarchical relationships (between health staff and patient or service provider and service user); the patient's level of education and ability to express their ideas; the position of women in the society in question; the patient's social standing, economic position and age. All of these factors combined to influence the respondent's ability or freedom to express their ideas, voice criticism and question figures of authority that may be perceived as belonging to the establishment as part of a government or charity-run health centre. The patient's voice was thus perceived to have been shaped by interpretation during interview, transcription, translation and the meaning assigned by the researcher. The research team examined and described the entire data set, while giving priority to the specific research questions of interest to the study. This approach is appropriate for new research areas such as in this case investigation of patient's experience of the diagnostic process (Braun and Clarke 2006). Themes were largely identified at a semantic or explicit level; however taking a contextualist standpoint, the researchers were sensitive to societal influences likely to have affected participants' accounts. Data was reduced to its core meaning, while at the same time, participants' terminology was retained as much as

possible by means of direct quotations or vignettes to illustrate the researcher's narrative (Braun and Clarke 2006).

Following the steps of the Thematic Analysis (Braun and Clarke 2006), data was prepared and managed by formatting, uploading and organising transcripts in computer-assisted data analysis software *NVivo* (QSR 2011). Patient demographics and details of interview location, date and interviewer were linked to the uploaded transcripts. A period of data familiarisation followed, during which the researcher read and re-read the transcripts by interview category and study site. The researcher began to list ideas about the content and noted issues of interest, under a theory-driven approach. A coding framework was developed (known in *NVivo* as a node structure) in consultation with research teams in Ethiopia and Yemen. Codes were grouped and positioned within a hierarchical structure, known as Parent and Child nodes. Data extracts were coded to the coding structure and the researcher noted tensions and inconsistencies between coding categories, which led to revision of the coding framework and node structure after coding of one fifth of the interview transcripts. Coded data extracts were reallocated to the new coding structure. Data was collated for each Code using the Framework Matrix facility within *NVivo*. The researcher took care to include one word or short responses in order to retain a balance of opinion alongside more detailed responses. Data for all patients (or cases) were collated by Code (Parent and Child Node). Data was reduced and summarised at the intersection of each Case and Node. Ideas were noted for themes and observations about decisions taken during the analysis and factors affecting interpretation of data were recorded for discussion in the thesis. Themes were developed, reviewed and refined by analysing the data contained against each code and testing for 'internal homogeneity' and 'external heterogeneity' as described by Patton (1990), cited by Braun and Clarke (2006). At this juncture, two analysis workshops were held at LSTM with study partners from Ethiopia and Yemen respectively, to check and discuss the meaning and interpretation of the data and formulation of key themes. These key themes provided a foundation for the development of broader theories and concepts.

## Chapter 4

### **Tuberculosis: the hidden cost of diagnosis**

#### **Introduction and background**

The financial consequences and costs of TB to the individual are significant. Several studies have shown the potentially ruinous financial effect of TB on the patient and his/her family – a cost which taken as a proportion of annual income disadvantages the poorest the most (Kemp et al. 2007; Lönnroth et al. 2010b; Yan et al. 2007). Costs to the patient include outgoings for non-specific medication, diagnostic and other tests, multiple consultations, transportation and loss of income (Cambanis et al. 2005a; Cambanis et al. 2007; Lönnroth et al. 2010b; Ramsay et al. 2010). It is well-known that these expenses are largely incurred before formal treatment begins, of which a substantial amount are incurred in the private sector (Karki et al. 2007; Lönnroth et al. 2010b). Regrettably, those that can least afford it also consult the private sector (Lönnroth et al. 2010b). Although treatment for TB is provided free of charge by most national control programmes, public health services often charge patients for the initial clinical consultation and diagnostic tests. As well as sputum smear microscopy, health staff often request additional diagnostic tests for which patients may be charged (WHO 2005). In addition to health system expenses, patient expenditure includes displacement costs from home, subsistence and indirect costs such as loss of earnings. Costs are increased by the need for patients to spend several days near the health facility to complete tests and collect results. The cost of diagnosis assumed by the patient therefore can be considerable. It is likely to contribute to the patient abandoning the diagnosis and is an important obstacle to accessing treatment services. While health service expenditure on diagnosis is easier to quantify, patient expenditure is less frequently reported and methodologies vary between studies. Few studies have isolated the cost of attending a formal health facility - i.e. one that is linked to the national TB control programme - for diagnosis, from clinic charges to related expenditure on subsistence and travel, both for the patient and those accompanying them, and have compared expense patterns across countries. This study thus focuses on the financial costs sustained by

patients attending TB diagnostic services in four countries and discerns whether expenses were incurred on the first or second day of clinic attendance, to ascertain whether accelerated diagnostic schemes would result in cost savings to the patient, as previously suggested (Cambanis et al. 2006a; Hirao et al. 2007).

A further point for consideration is that expenses associated with attendance for diagnosis are unlikely to be homogeneous across the population, with some population groups having higher than average expenses and therefore carrying a higher risk of defaulting. Identifying these groups would be of value to health programmes, as well as policy makers and potentially contribute to the development of screening interventions to support patients with limited resources and high expenditure.

This study therefore examines the financial cost of clinic attendance for TB diagnosis for each day of the diagnostic process in Ethiopia, Nepal, Nigeria and Yemen and identifies factors associated with and risk factors for high expenditure, with a view to improving access and adherence to diagnosis. The study also compares cost patterns across countries and assesses whether accelerated diagnostic approaches would lead to significant savings for patients. This information is then used to identify groups of the population that have higher costs for diagnosis and to develop a score to screen patients likely to incur higher costs.

## **Methods**

This was a cross sectional survey of adults with chronic cough attending health facilities in four countries.

### **Study setting**

The study sites were selected on the basis that they were located in countries with moderate to high disease prevalence and were integrated within their respective National TB Control Programme. The main enrolment centre in each site was: **Ethiopia** - Bushullo Major Health Centre a general primary care centre in Awassa; **Nepal** - Tribhuvan University Teaching Hospital in Kathmandu, a

governmental referral hospital for pulmonary diseases including TB; **Nigeria** - Wuse General Hospital, a government general hospital in Abuja; and **Yemen** - the NTI in Sana'a, a government referral centre for TB. The centres have the following approximate patient numbers each month: **Ethiopia** - 60 new cases of TB are diagnosed from 260 patients seen; **Nepal** - 200 new cases diagnosed from 1000 monthly patients seen; **Nigeria** - 50 new cases from 250 patients seen and **Yemen** - 120 new cases from 780 patients. Individuals attending the centres either self-refer or are referred by surrounding health centres and sometimes by private or informal health care providers.

### **Data collection**

The same study protocol was implemented in the four study settings. Adults over 18 years old with cough of more than 2 weeks duration were interviewed on their first attendance at TB diagnostic centres once informed consent had been obtained. Patients were interviewed between January 2008 and March 2009. Standard questionnaires were used to obtain background, practical and clinical information and establish the costs associated with travelling to the centre and staying overnight to attend the second day of the diagnostic process. Patients described how they had travelled to the clinic, their journey time, whether or not they had come alone and reported costs incurred to date and projected costs for returning to the clinic for a second day. A minimum of 500 hundred patients were recruited from each country (504 from Ethiopia, 619 from Nepal, 502 from Nigeria and 600 from Yemen), creating a total of 2225 patients. In each setting, patients were enrolled consecutively, with a maximum of 10 interviews undertaken each day. All patients underwent routine smear microscopy and one sputum specimen was cultured.

### **Data analysis**

Information was collected using structured questionnaires and data was entered in a database using Epi-Info, a statistical software package for epidemiology. The characteristics of the participants were described using descriptive summary statistics by study site. The proportions of patients with a specific characteristic were compared using chi squares and means were compared using parametric statistics for normally distributed data and non-parametric tests for skewed data. Most costs

incurred by patients were described using medians and 25<sup>th</sup>-75<sup>th</sup> interquartile ranges, as many items had skewed distributions and the total cost incurred each day was obtained by adding the figures for the day.

This was followed by a description of the median expenditure of patients stratified by their characteristics (e.g. median expenditure of patients from rural and urban areas), to identify characteristics associated with high expenditure.

Patients with an expenditure above the 75<sup>th</sup> quartile were then classified as 'cases' and patients with costs below the 75<sup>th</sup> quartile were classified as 'controls', to identify risk factors for high expenditure in each setting. The analysis included calculating Odds Ratios (OR) with 95% confidence intervals.

OR with p values <0.2 were then entered into a logistic regression to identify adjusted OR (AOR) that were statistically associated with high expenditure.

Finally, we attempted to develop a score that could identify patients likely to have high expenditure.

The score of a patient was based on the sum of the odds ratios of all risk factors present. If the risk factor was present, a weight equivalent to the OR was added to the score. The same process was employed for cases and controls. Scores were then used to define Receiver Operator Curves to calculate cut-offs for sensitivity and specificity of the score, to identify individuals with high expenditure and exclude those with low costs.

### **Ethical approval**

Ethical approval for the study protocols was obtained from the research ethics committees of the Liverpool School of Tropical Medicine and the Institutional Review Boards of the participating institutions in Ethiopia, Nepal, Nigeria, and Yemen.

### **Results**

The results are presented for each country, followed by the combined results for all countries.

### **Demographic profile**

The demographic characteristics of patients by country are shown in table 4.1. The mean (SD) age of the patients was 39 (17) years. Patients in Ethiopia and Nigeria were younger (33 and 34 years

respectively) than in Yemen and Nepal (42 and 44 years) ( $p=0.001$ ). There was a higher percentage of males than females in all study sites except for Nigeria (48%). The majority of patients (1494/2225, 67%) described themselves as being married or having a partner; 590 (27%) were single; 103 (5%) widowed and a small minority divorced or separated (35, 2%). A sizeable number of patients in each country was resident in a rural area, ranging from 63 (10%) in Nepal to 182 (36%) and 279 (47%) in Ethiopia and Yemen. The vast majority of patients living in a town or city in Nigeria and Yemen were resident in the city where the health centre was located (98% and 83%); while in Nepal, city dwellers were fairly evenly divided between Kathmandu and other towns.

Literacy among participants was highest in Nigeria (88%), where 220 (44%) patients had attended secondary and 133 (27%) tertiary education. This was followed by Nepal with 475 (77%) patients being literate of whom 153 (25%) had been in tertiary education. Ethiopia and Yemen had the lowest educational level. The percentage of patients that described themselves as currently working was 44% (969), with the highest proportion of patients working observed in Nigeria and the lowest in Yemen. The most common occupation in Ethiopia was farming (25%) followed by a housewife (24%), while the order was reversed in Nepal and Yemen. In Nigeria, only 32/502 (6%) patients worked in farming and 22 (4%) as housewives, whereas 86 (17%) worked for the Government and 290 (58%) in unspecified employment categories. The number of patients working as daily labourers ranged from 21 (3%) in Nepal to 71 (12%) in Yemen, and Nepal was the only country where a sizeable number of patients worked as merchants (97, 16%). The number of students on the other hand was fairly constant across the host countries at an average of 10%.

The mean (SD) number of residents per household across the study settings was 6.1 (4) residents, with Yemen having the highest mean (SD) number per household (8.6, 5) and Nigeria the lowest (4.1, 3). Households had a mean (SD) of 3.1 (3.3) rooms excluding the kitchen and bathroom, resulting in 3 residents per room in Ethiopia, 2.2 in Yemen, 1.8 in Nigeria and 1.4 in Nepal.

**Table 4.1: Description of patients' demographic characteristics by country**

Variable*		Ethiopia N=504	Nepal N=619	Nigeria N=502	Yemen N=600	All N=2225	P value
Mean age (SD)		33.2 (14.5)	43.8 (17.8)	34.4 (11)	41.8 (18.3)	38.7 (16.6)	<0.001
Male: Female (% male)		279: 225 (55.4)	395: 224 (63.8)	241: 258 (48.0)	329: 271 (54.8)	1244: 978 (55.9)	<0.001
Marital status	Single	176 (34.9)	107 (17.3)	183 (36.5)	124 (20.7)	590 (26.5)	<0.001
	With partner/married	302 (59.9)	507 (81.9)	259 (51.6)	426 (71)	1494 (67.1)	<0.001
	Divorced/separated	12 (2.4)	0 (0)	13 (2.6)	10 (1.7)	35 (1.6)	0.002
	Widowed	14 (2.8)	5 (0.8)	44 (8.8)	40 (6.7)	103 (4.6)	<0.001
Residence	Rural	182 (36.1)	63 (10.2)	82 (16.3)	279 (46.5)	606 (27.2)	<0.001
	Same town	216 (42.9)	284 (45.9)	410 (81.7)	268 (44.7)	1178 (52.9)	<0.001
	Other town	106 (21)	272 (43.9)	7 (1.4)	53 (8.8)	438 (19.7)	<0.001
Literate: Illiterate (% literate)		247: 257 (49)	475: 137 (76.7)	439: 57 (87.5)	264: 336 (44.0)	1425: 787 (64)	<0.001
	Missing	0 (0)	7 (1.1)	6 (1.2)	0 (0)	13 (0.6)	
Education	Nil	257 (51)	197 (31.8)	41 (8.2)	311 (51.8)	806 (36.2)	<0.001
	Primary incomplete	117 (23.2)	37 (6)	42 (8.4)	126 (21)	322 (14.5)	<0.001
	Primary complete	43 (8.5)	105 (17)	63 (12.5)	56 (9.3)	267 (12)	<0.001
	Secondary	62 (12.3)	127 (20.5)	220 (43.8)	61 (10.2)	470 (21.1)	<0.001
	Tertiary	24 (4.8)	153 (24.7)	133 (26.5)	46 (7.7)	356 (16)	<0.001
		Missing	1 (0.2)	0 (0)	3 (0.6)	0 (0)	4 (0.2)
Working: not working (% working)		235: 269 (46.6)	202: 417 (32.6)	368: 131 (73.3)	164: 436 (27.3)	969: 1253 (43.6)	<0.001
Occupation	Farmer	125 (24.8)	133 (21.5)	32 (6.4)	140 (23.3)	430 (19.3)	<0.001
	Student	47 (9.3)	66 (10.7)	47 (9.4)	58 (9.7)	218 (9.8)	0.857
	Housewife	121 (24)	146 (23.6)	22 (4.4)	210 (35)	499 (22.4)	<0.001
	Daily labourer	38 (7.5)	21 (3.4)	21 (4.2)	71 (11.8)	151 (6.8)	<0.001
	Merchant	33 (6.5)	97 (15.7)	1 (0.2)	8 (1.3)	139 (6.2)	<0.001
	Government	45 (8.9)	33 (5.3)	86 (17.1)	62 (10.3)	226 (10.2)	<0.001
	Other	92 (18.3)	117 (18.9)	290 (57.8)	51 (8.5)	550 (24.7)	<0.001
		Missing	3 (0.6)	6 (1)	3 (0.6)	0 (0)	12 (0.6)
Mean N residents in household (SD)		5.7 (2.9)	5.5 (3)	4.1 (3)	8.6 (5)	6.1 (4)	<0.001
Mean N rooms (SD)		1.9 (1.2)	4.0 (5)	2.3 (2.5)	3.9 (2.2)	3.1 (3.3)	<0.001

\* Data represent frequency (%), unless otherwise specified. Sex, residency, marital and work status were missing for 3 patients in Nigeria.

### **Transport, companionship and overnight accommodation**

The practical arrangements associated with clinic attendance such as travel, companionship and overnight accommodation are shown in table 4.2. More than 70% of patients in Yemen, Ethiopia and Nepal were accompanied, with nearly all (85%) patients in Yemen attending with company. In contrast, only a third of patients (35%) in Nigeria came with another person. Of those patients that were accompanied, 224 (15%) came with their husband or wife (range 10% in Yemen to 28% in Nigeria) and the majority (77%) attended with another relative (range from 53% in Nigeria to 86% in Yemen). Few patients were accompanied by a friend or neighbour.

The most common method of transport for the first day of attendance was the bus in Nigeria, Nepal and Ethiopia, followed by the taxi then car. In Yemen, more patients travelled by taxi or car than by bus. Travelling by horse and cart, or on horseback, was widespread in Ethiopia (129: 26%) compared with less than 1% of patients in other countries. Nepal was the only country in which motorbikes were commonly used (104, 17%). Few patients across the study sites (<1%) came by bicycle (21) or were carried to the clinic (8). A fair number of patients in Nepal and Ethiopia came on foot (92, 15% and 67, 13%) while only 2% of patients in Nigeria and Yemen walked.

The median (25% - 75% IQR) time patients travelled from home to the health centre was 40 minutes (20 mins - 1 hr 6 mins). Patients in Nepal had the shortest travel time at 25 minutes (15 - 30 mins) and patients in Yemen the longest at 1 hour (30 mins - 2 hrs 30 mins). In Ethiopia and Nigeria patients spent 45 minutes travelling (27 mins - 2 hrs and 30 mins - 1 hr, respectively).

In order to return for the second day of consultation, the majority of patients expected to travel (as on the first day) by bus (794; 36%), then taxi (580; 26%) and car (204; 18%). Again, patients in Yemen differed with an increased number (327: 55%) expecting to travel by taxi on the second day and a decrease of 16% in the number of patients that anticipated travelling by car (109: 18%). More patients in Ethiopia intended to come by horse and cart or on horseback (181: 36%), on foot (118: 23%), or by taxi (108: 21%) than on the first day.

Patients indicated where they intended to stay overnight. In Ethiopia, Nigeria and Yemen, the majority of patients intended to stay at home (358, 71%; 437, 87% and 407, 68%), while in Nepal 46% planned to stay with a relative. The number of patients admitted to hospital was higher in Nigeria (54, 11%) than in the other study sites (20 (3%) in Nepal, 15 (3%) in Ethiopia and 2 (<1%) in Yemen). In Ethiopia, Yemen and Nepal, 13%, 11% and 7% of the patients planned to pay for a hotel. Shift accommodation featured very little (6 patients in Nepal and 1 in Ethiopia) and only three patients envisaged sleeping on the street.

### **Costs associated with attending the clinic**

The total direct and anticipated costs incurred by patients for attending the clinic on the first and second day are summarised in table 4.3. Overall, the most significant expenditure was on clinic fees and transport (although patients in Nigeria spent little on clinic fees). Patients in Ethiopia and Yemen anticipated spending less on transportation on the second day than on the first; while patients in Nepal and Nigeria expected first and second day expenditure to be comparable. Expenditure on food on the first day was very low and second day expenditure was expected to be similar. Median (25% & 75% IQR) patient expenditure on overnight accommodation was 0 in all 4 countries. Patients also reported incurring additional unspecified expenses in Nepal (509, 83%), Yemen (73, 12%) and Nigeria 13 (3%) and these were substantial. In Nepal, additional expenses constituted the most important costs alongside clinic fees. Estimated second day expenses were the same as first day expenses, with the exception of Yemen, where patients expected to have fewer outgoings due to reduced transport costs.

The median cost (in US\$) of attending the clinic for 2 days was highest in Yemen (\$11.89), followed by Nepal (\$8.22), Nigeria (\$5) and Ethiopia (\$1.47). In Yemen, the most important outgoings for patients were transport costs, followed by miscellaneous (unspecified) expenses for a small number of patients, then clinic fees. In Nepal, the cost of clinic fees and miscellaneous unspecified expenses accounted for the majority of expenditure. In Nigeria, transportation accounted for the most significant costs and the same was true for patients in Ethiopia, followed by clinic fees.

**Table 4.2: Clinic attendance**

Variable*		Ethiopia N=504	Nepal N=619	Nigeria N=502	Yemen N=600	All N=2225	P value
Alone: With company (% with company)		129: 373 (74)	181: 435 (70.3)	320: 177 (35.3)	91: 509 (84.8)	721: 1494 (67.1)	<0.001
	Missing	2 (0.4)	3 (0.5)	5 (1)	0 (0)	10 (0.4)	
Person accompanying	Husband/wife	61 (16.4)	62 (14.3)	50 (28.2)	51 (10)	224 (15)	0.268
	Other relative	276 (74)	336 (77.2)	94 (53.1)	439 (86.2)	1145 (76.6)	<0.001
	Friend	13 (3.5)	17 (3.9)	19 (10.7)	17 (3.3)	66 (4.4)	0.666
	Neighbour	7 (1.9)	10 (2.3)	1 (0.6)	0 (0)	18 (1.2)	0.001
	Other	16 (4.3)	9 (2.1)	13 (7.3)	2 (0.4)	40 (2.7)	0.003
	Missing	0 (0)	1 (0.2)	0 (0)	0 (0)	1 (0.1)	
Main transport first day	Walked	67 (13.3)	92 (14.9)	12 (2.4)	12 (2)	183 (8.2)	0.001
	Carried	6 (1.2)	0 (0)	2 (0.4)	0 (0)	8 (0.4)	
	Bicycle	14 (2.8)	7 (1.1)	0 (0)	0 (0)	21 (0.9)	
	Cart/horse	129 (25.6)	5 (0.8)	0 (0)	4 (0.7)	138 (6.2)	
	Motorbike	1 (0.2)	104 (16.8)	2 (0.4)	3 (0.5)	110 (4.9)	
	Bus	148 (29.4)	303 (48.9)	303 (60.4)	127 (21.2)	881 (39.6)	
	Car	33 (6.5)	14 (2.3)	76 (15.1)	203 (33.8)	326 (14.7)	
	Taxi	103 (20.4)	83 (13.4)	101 (20.1)	250 (41.7)	537 (24.1)	
	Other	1 (0.2)	8 (1.3)	1 (0.2)	1 (0.2)	11 (0.5)	
	Missing	2 (0.4)	3 (0.5)	5 (1)	0 (0)	10 (0.4)	
Median travel time from home (25%; 75% IQR) <sup>1</sup>		45 mins (27 mins; 2 hrs)	25 mins (15 mins; 30 mins)	45 mins (30 mins; 1 hr)	1 hr (30 mins; 2 hrs 30 mins)	40 mins (20 mins; 1 hr 6 mins)	0.001
Accommodation	Home	358 (71)	267 (43.1)	437 (87.1)	407 (67.8)	1469 (66)	<0.001
	Relative	60 (11.9)	282 (45.6)	5 (1)	123 (20.5)	470 (21.1)	<0.001
	Hotel	66 (13.1)	40 (6.5)	0 (0)	68 (11.3)	174 (7.8)	<0.001
	Street	2 (0.4)	0 (0)	1 (0.2)	0 (0)	3 (0.1)	0.224
	Shift	1 (0.2)	6 (1.0)	0 (0)	0 (0)	7 (0.3)	0.007
	Hospital	15 (3.0)	20 (3.2)	54 (10.8)	2 (0.3)	91 (4.1)	<0.001
	Missing	2 (0.4)	4 (0.7)	5 (1)	0 (0)	11 (0.4)	
Anticipated transport	Walking	118 (23.4)	104 (16.8)	13 (2.6)	12 (2)	247 (11.1)	<0.001
	Being carried	3 (0.6)	2 (0.3)	2 (0.4)	1 (0.2)	8 (0.4)	0.694

	Bicycle	13 (2.6)	9 (1.5)	0 (0)	0 (0)	22 (1)	<0.001
	Cart/horse	181 (35.9 )	5 (0.8)	0 (0)	5 (0.8)	191 (8.6)	<0.001
	Motorbike	1 (0.2)	104 (16.8)	1 (0.2)	3 (0.5)	109 (4.9)	<0.001
	Bus	44 (8.7)	298 (48.1)	309 (61.6)	143 (23.8)	794 (35.7)	<0.001
	Car	29 (5.8)	13 (2.1)	53 (10.6)	109 (18.2)	204 (18.2)	<0.001
	Taxi	108 (21.4)	72 (11.6)	73 (14.5)	327 (54.5)	580 (26.1)	<0.001
	Other	5 (1)	9 (1.5)	38 (7.6)	0 (0)	52 (2.3)	<0.001
	Missing	2 (0.4)	3 (0.5)	13 (2.6)	0 (0)	18 (0.8)	

\* Data represent frequency (%), unless otherwise specified.

<sup>1</sup> Travel time of 0 minutes was excluded.

**Table 4.3: Direct costs incurred for each day of attendance in local currency**

Variable <sup>1</sup>	Ethiopia ETB N=504	Nepal NPR N=619	Nigeria NGN N=502	Yemen YER, N=600
Proportion of poor/general population (H) using MPI <sup>2</sup>	0.900	0.647	0.635	0.525
Proportion of poor/general population <1.25\$/day <sup>3</sup>	0.390	0.551	0.644	0.175
Conversion rate to USD	1=0.0610833	1=0.0136054	1=0.00658111	1=0.00466200
<b>First day expenses<sup>4</sup></b>				
Transport costs	8 (2; 24)	24 (0; 52)	200 (100; 340)	1000 (400; 2050)
Food	0 (0; 6)	0 (0; 0)	100 (0; 200)	0 (0; 200)
Subtotal	8 (3; 32)	36 (0; 80)	300 (180; 490)	1040 (500; 2400)
Subtotal (US \$)	0.49	0.49	1.97	4.85
<b>Second day expenses (anticipated)</b>				
Food (as first day)	0 (0; 6)	0 (0; 0)	100 (0; 200)	0 (0; 200)
Overnight accommodation	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
Transport	6 (0; 8)	24 (0; 48)	200 (60; 300)	600 (300; 1000)
Subtotal	8 (3; 18)	36 (0; 80)	300 (160; 400)	800 (400; 1400)
Subtotal (US \$)	0.49	0.49	1.97	3.73
<b>Cost of attending 2 days (estimated)</b>				
Patients incurring other expenses N (%) <sup>5</sup>	0 (0)	509 (82.6)	13 (2.6)	73 (12.2)
Other expenditure	0 (0; 0)	300 (200; 300)	500 (200; 1000)	1000 (500; 2000)
Clinic fees	8 (5; 8)	300 (300; 300)	0 (0; 150)	450 (250; 450)
Transport	16 (4; 36)	48 (0; 100)	400 (200; 600)	2000 (800; 3400)
Food	0 (0; 12)	0 (0; 0)	200 (0; 400)	0 (0; 400)
Overnight accommodation	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
Total	24 (11; 58)	604 (500; 900)	760 (420; 1400)	2550 (1400; 4850)
Total (US \$)	1.47	8.22	5.00	11.89

<sup>1</sup> Values are medians and 25-75% interquartile ranges (IQR) and given in the local currency, unless specified otherwise.

<sup>2</sup> The figures are derived from the Multidimensional Poverty Index (Alkire & Santos 2010).

<sup>3</sup> Proportion of people living on < \$1.25/day, World Development Indicators, World Bank 2009.

<sup>4</sup> First and second day costs exclude clinic fees and additional expenses.

<sup>5</sup> Data missing for 10 patients (2 in Ethiopia, 3 in Nepal and 5 in Nigeria).

### Costs incurred by population subgroup

The median (25% and 75% IQR) costs incurred by subgroups of the population for two days of attendance at diagnostic services are presented in table 4.4.

The factors associated with higher patient expenditure were attending with company, place of residence, work status and occupation. In Ethiopia and Yemen, patients living in another town experienced higher costs than those residing in a rural area or the town in which the clinic was located. In Nepal, rural residents paid more than urban residents. In all 4 study sites, patients that were accompanied had increased expenses, as did those that were not working, although the difference in cost for the latter category was not significant in Ethiopia. The occupations associated with higher costs were being a farmer, a student (except for Yemen) or housewife (except for Nigeria). In Ethiopia, Nepal and Yemen, farmers faced the highest costs, while in Nigeria this was the case for labourers. Differences in expenditure according to occupation were not significant in Nepal.

Patients' expenses were not associated with biological sex or completion/non completion of the diagnostic process. Smear and culture positivity were associated with higher costs in Nepal alone.

In summary, the factors associated with increased patient expenditure after univariate analysis, in order of significance, were: in **Ethiopia**, living in another town, being accompanied to the clinic and being a farmer, housewife or student; in **Nigeria**, being accompanied, not working at the time of consultation and being a labourer, student or farmer; in **Yemen**, living in another town, being accompanied, being a farmer, housewife, or government employee and not working and in **Nepal**, residing in a rural area, being accompanied, having longer duration of illness and cough of 5 to 11 weeks, not working, being over 50, and smear and culture positivity.

**Table 4.4: Costs incurred by population subgroup**

Variable <sup>6</sup>	Ethiopia N=504		Nepal N=619		Nigeria N=502		Yemen N=600	
	N	ETB	N	NPR	N	NGN	N	YER
Age <20 yr	52	21 (8; 48)	37	600 (500; 740) <sup>c</sup>	13	1100 (850; 2300) <sup>d</sup>	54	2240 (1400; 3850)
20 to 49	367	24 (11; 58)	332	600 (500; 858)	444	725 (400; 1390)	312	2550 (1400; 4795)
50 or more	83	26 (12; 60)	250	640 (560; 980)	40	800 (525; 1800)	232	2760 (1445; 5050)
Male	278	24 (11; 56)	395	610 (500; 976)	241	700 (420; 1400)	328	2525 (1305; 4650) <sup>d</sup>
Female	224	24 (11; 60)	224	600 (500; 849)	256	800 (480; 1400)	271	2600 (1600; 5450)
Rural resid.	182	43 (24; 79) <sup>a</sup>	63	725 (460; 1890) <sup>a</sup>	82	700 (480; 1400)	279	3890 (2250; 6250) <sup>a</sup>
Same town	215	12 (5; 24)	284	598 (500; 749)	408	760 (400; 1400)	267	1650 (890; 2654)
Other town	105	56 (40; 82)	272	648 (572; 895)	7	1660 (850; 1800)	53	4250 (2450; 7360)
Alone	129	9 (5; 14) <sup>a</sup>	181	600 (500; 750) <sup>b</sup>	320	645 (400; 1100) <sup>a</sup>	90	1420 (800; 2450) <sup>a</sup>
Accompan.	373	38 (24; 72)	435	620 (500; 980)	177	1100 (600; 1900)	509	2850 (1650; 5250)
Diagnosis complete	488	24 (11; 58) \$1.47	602	600 (500; 885) \$8.16	423	750 (400; 1400) \$4.94	569	2550 (1400; 4890) \$11.89
Diagnosis incomplete	14	27.5 (8; 48) \$1.68	16	868 (400; 1188) \$11.81	47	750 (500; 1400) \$4.94	30	2675 (1650; 4050) \$12.47
Smear +	111	28 (13; 53)	71	700 (560; 1160) <sup>c</sup>	85	800 (480; 1400)	120	2610 (1450; 4850)
Smear -	389	24 (11; 58)	545	600 (500; 850)	403	740 (400; 1400)	476	2550 (1400; 4930)
Culture +	141	29 (13; 56) <sup>d</sup>	73	672 (580; 1160) <sup>c</sup>	80	770 (400; 1400)	150	2535 (1400; 4800)
Culture -	345	24 (11; 58)	515	600 (500; 840)	399	760 (420; 1400)	430	2555 (1450; 5050)
Duration ill								
1 & 2 weeks	90	24 (11; 48) <sup>d</sup>	63	540 (270; 1200) <sup>b</sup>	133	750 (420; 1400)	162	2625 (1510; 5050)
3 and 4	153	24 (9; 52)	153	596 (500; 780)	144	800 (400; 1400)	140	2400 (1325; 4610)
5 to 11	120	38 (17; 64)	129	600 (540; 950)	91	800 (400; 1440)	131	2850 (1350; 4890)
12 or more	137	24 (11; 72)	271	640 (560; 976)	118	700 (500; 1220)	153	2480 (1550; 4750)

<sup>6</sup> Values are medians and 25-75% interquartile ranges (IQR) and given in the local currency, unless specified otherwise.

<sup>a</sup> P <0.001, <sup>b</sup> P <0.01, <sup>c</sup> P <0.05, <sup>d</sup> P <0.2

Variable <sup>7</sup>	Ethiopia N=504		Nepal N=619		Nigeria N=502		Yemen N=600	
	N	ETB	N	NPR	N	NGN	N	YER
Cough dura.n								
1 & 2 weeks	95	24 (11; 48) <sup>d</sup>	80	565 (300; 1148) <sup>b</sup>	165	800 (400; 1500)	196	2650 (1455; 5100)
3 and 4	160	24 (9; 50)	169	600 (500; 800)	134	740 (400; 1380)	132	2450 (1450; 4725)
5 to 11	115	36 (16; 64)	130	630 (540; 1020)	84	800 (490; 1440)	118	2425 (1250; 4750)
12 or more	128	24 (11.5; 72)	238	623 (580; 900)	104	700 (500; 1370)	138	2515 (1610; 4750)
Working	234	24 (10; 56)	202	598 (500; 780) <sup>b</sup>	367	700 (400; 1300) <sup>b</sup>	163	2150 (1090; 4050) <sup>b</sup>
Not work.g	268	28 (11.5; 63)	417	640 (540; 900)	130	1000 (520; 1600)	436	2650 (1580; 5100)
Farmer	125	52 (24; 80) <sup>a</sup>	133	648 (552; 980)	32	800 (535; 1600) <sup>c</sup>	140	3375 (2000; 6050) <sup>a</sup>
Student	47	24 (11; 52)	66	640 (500; 900)	46	1150 (550; 1900)	58	2250 (1250; 4050)
Housewife	121	42 (24; 73)	146	611.5 (500; 848)	22	690 (400; 1040)	210	2850 (1650; 6050)
Labourer	38	11 (5; 21)	21	600 (480; 1080)	21	1200 (640; 1440)	71	2050 (1120; 3250)
Merchant	32	22.5 (8; 52)	97	600 (536; 720)	1	20000 (-; -)	8	1925 (975; 2950)
Governm.t	45	13 (7; 27)	33	600 (540; 700)	86	720 (400; 1300)	61	2500 (1250; 4250)
Other	92	16 (8; 27.5)	117	600 (500; 975)	289	700 (400; 1320)	51	1300 (800; 2950)

<sup>7</sup> Values are medians and 25-75% interquartile ranges (IQR) and given in the local currency, unless specified otherwise.

<sup>a</sup> P < 0.001, <sup>b</sup> P < 0.01, <sup>c</sup> P < 0.05, <sup>d</sup> P < 0.2

### **Risk factors for higher patient expenditure**

Risk factors for higher expenditure were further analysed using a logistic regression (LR) analysis.

For this purpose, cases with high expenditure were defined as patients having total expenses above the 75th quartile. The cut-off point for the quartiles was calculated for each study setting by combining all cost estimates described in the previous sections to obtain the total costs and calculating the quartile distribution of costs. Then, variables associated with high expenditure at the univariate level and p values < 0.2 were selected for the LR.

A total of 538 cases of high expenditure and 1679 controls were analysed (Appendix 10). Odds ratios for each study site are shown in table 4.5. Although there are considerable differences between countries, several variables had statistically significant associations with high expenditure across various settings. Rural/other town residency, low education, illiteracy and being accompanied at the time of consultation were risk factors for high expenditure in Ethiopia, Nepal and Yemen. Of these, only illiteracy and being accompanied were also statistically significant in Nigeria. Of note, cases in Ethiopia were 23 and 19 times more likely to reside in rural areas/other towns and to attend with company than controls. Not working at the time of consultation was a risk factor in Nigeria and Yemen as were certain occupations such as being a farmer, student, housewife or labourer in Ethiopia and Yemen.

The logistic regressions by country are shown in table 4.6. Variables independently associated with high expenditure in Ethiopia and Yemen were rural/other town residency and attending the clinic with company (Ethiopia AOR [95%CI] 15.3, [6.46-36.02] and 7.5, [2.25-25.18], respectively; Yemen 6.7 [4.1-10.96] and 3.1 [1.46-6.45], respectively). In Nigeria, attending with company (AOR 2.5, [1.64-3.88]) and illiteracy (AOR 1.9 [1.04-3.43]) were independent risk factors for high expenditure. Illiteracy was a significant risk factor in Nepal (AOR 2.5 [1.51-3.98]), along with male sex (AOR 2.0 [1.25-3.15]) and culture positivity (AOR 2.3 [1.33-3.81]).

Odds ratios for the logistic regression for all countries combined are shown in table 4.7 and examples of the process are shown in Appendix 11. Age over 50 years, rural/other town residency, illiteracy, having no to primary level education, attending the clinic with company, not being in work at the time of consultation and being a farmer, student, housewife or daily labourer, were statistically associated with high expenditure across the study population. Rural/other town residency and attending the clinic with company had the highest OR (2.82, 95%CI 2.3-3.46 and 2.5, 95%CI 1.97-3.17 respectively), signifying that patients with high expenditure were two times more likely to reside in rural areas or other towns and to attend with company than controls. Attending the service with company (AOR 2.0, 95%CI 1.58-2.57) and rural/other town residency (AOR 2.5, 95% CI 2.01-3.05) were the two variables that remained independently associated with high expenditure after the LR.

**Table 4.5: Risk factors for higher patient expenditure, odds ratios by country**

Variable	Ethiopia		Nepal		Nigeria		Yemen	
	OR <sup>1</sup> (95% CI <sup>2</sup> )	p <sup>3</sup>	OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p
Age 50 or more	1.07 (0.62-1.84)	0.46	1.26 (0.86-1.82)	0.14	1.59 (0.79-3.20)	0.13	1.28 (0.88-1.86)	0.12
Male sex	0.89 (0.59-1.35)	0.33	1.40 (0.94-2.09)	0.06	1.06 (0.70-1.60)	0.43	0.73 (0.51-1.06)	0.06
With partner/married	1.95 (1.25-3.03)	<0.002	0.83 (0.52-1.32)	0.25	1.01 (0.67-1.53)	0.52	1.11 (0.73-1.67)	0.36
Residency rural/other town	23.63 (10.15-55.02)	<0.001	1.49 (1.02-2.17)	0.02	1.05 (0.62-1.79)	0.47	6.90 (4.23-11.25)	<0.001
Illiterate	1.90 (1.25-2.89)	<0.002	1.71 (1.12-2.60)	0.01	2.40 (1.35-4.27)	0.003	1.71 (1.16-2.52)	0.004
Education nil, primary incomplete, primary complete	2.48 (1.27-4.84)	0.003	1.44 (0.98-2.09)	0.04	1.06 (0.67-1.66)	0.45	1.91 (1.10-3.34)	0.01
Accompanied	19.68 (6.13, 63.12)	<0.001	1.46 (0.96-2.24)	<0.05	2.73 (1.79-4.16)	<0.001	3.41 (1.67-6.98)	<0.001
Smear positive (1 or more + smear)	0.88 (0.53-1.44)	0.35	2.22 (1.32-3.74)	<0.01	0.83 (0.47-1.46)	0.30	0.95 (0.59-1.51)	0.46
Culture positive	0.99 (0.63-1.55)	0.52	2.21 (1.32-3.69)	<0.01	0.99 (0.56-1.73)	0.55	0.89 (0.58-1.38)	0.35
Illness duration 12 weeks or more	1.56 (1.01-2.43)	0.03	1.19 (0.82-1.73)	0.21	0.89 (0.54-1.46)	0.37	0.94 (0.61-1.45)	0.43
Cough duration 5 to 11 weeks	1.26 (0.78-2.01)	0.20	1.34 (0.86-2.07)	0.12	1.15 (0.67-1.97)	0.35	0.97 (0.60-1.56)	0.5
Not currently working	1.24 (0.82-1.87)	0.18	1.14 (0.77-1.71)	0.29	1.71 (1.09-2.67)	0.01	1.36 (0.88-2.10)	<0.1
Occupation farmer, student, housewife, labourer	3.79 (2.21-6.51)	<0.001	1.11 (0.76-1.63)	0.33	1.41 (0.89-2.25)	0.09	2.30 (1.33-4.00)	0.001

<sup>1</sup> OR - Odds Ratio

<sup>2</sup> CI - Confidence Interval

<sup>3</sup> P - P value

**Table 4.6: Independent risk factors for higher patient expenditure by country**

Variable	Ethiopia		Nepal		Nigeria		Yemen	
	AOR <sup>1</sup> (95% CI)	p	AOR (95% CI)	p	AOR (95% CI)	p	AOR (95% CI)	p
Age 50 or more								
Male sex			1.99 (1.25-3.15)	<0.01				
With partner/married								
Residency rural/other town	15.26 (6.46-36.02)	<0.001					6.7 (4.1-10.96)	<0.001
Illiterate			2.45 (1.51-3.98)	<0.001	1.89 (1.04-3.43)	0.04		
Education nil, primary incomplete, primary complete								
Accompanied	7.53 (2.25-25.18)	0.001			2.52 (1.64-3.88)	<0.001	3.07 (1.46-6.45)	<0.01
Smear positive (1 or more + smear)								
Culture positive			2.25 (1.33-3.81)	<0.01				
Illness duration 12 weeks or more								
Cough duration 5 to 11 weeks								
Not currently working								
Occupation farmer, student, housewife, labourer								

<sup>1</sup> AOR – Adjusted Odds Ratio

**Table 4.7: Risk factors for higher patient expenditure, all countries combined**

<b>Variable</b>	<b>Case N= 538 (Col%)</b>	<b>Control N = 1679 (Col%)</b>	<b>OR (95% CI)</b>	<b>p</b>	<b>AOR (95% CI)</b>	<b>p</b>
Age 50 or more	164 (30.5)	441 (26.3)	1.23 (<1.0-1.53)	0.03		
Male sex	300 (55.8)	942 (56.1)	0.99 (0.81-1.2)	0.46		
With partner/married	375 (69.7)	1115 (66.4)	1.16 (0.94-1.44)	0.09		
Residency rural/other town	356 (66.2)	687 (40.9)	2.82 (2.3-3.46)	<0.001	2.48 (2.01-3.05)	<0.001
Illiterate	242 (45.1)	545 (32.6)	1.69 (1.39-2.07)	<0.001		
Education nil, primary incomplete, primary complete	370 (68.8)	1024 (61)	1.41 (1.15-1.73)	<0.001		
Accompanied	436 (81)	1058 (63.1)	2.5 (1.97-3.17)	<0.001	2.02 (1.58-2.57)	<0.001
Smear positive (1 or more + smear)	99 (18.6)	288 (17.3)	1.09 (0.85-1.41)	0.27		
Culture positive	116 (21.6)	328 (19.5)	1.13 (0.89-1.44)	0.17		
Illness duration 12 weeks or more	173 (32.9)	506 (30.4)	1.12 (0.9-1.38)	0.16		
Cough duration 5 to 11 weeks	119 (22.5)	328 (19.8)	1.18 (0.93-1.49)	0.1		
Not currently working	329 (61.2)	922 (54.9)	1.29 (1.06-1.58)	<0.01		
Occupation farmer, student, housewife, labourer	360 (67.3)	937 (56)	1.62 (1.32-1.99)	<0.001		

## **Scores to identify patients with high expenditure**

Two scores were developed to identify patients with high expenditure. One score selected the variables associated with high expenditure across the entire study population – called here the *generic score* and a second score selected variables associated with high expenditure for each country – the *country-specific score*.

### **Generic score**

After calculating the total score (the sum of the OR for each patient), cases' and controls' scores were used to calculate a ROC as shown in figure 4.1. The score had an Area Under the Curve (AUC) of 0.64, meaning 64% of patients were correctly classified as high/not-high spenders. The best cut-off value selected by the software was a score of 11.75, which achieved a sensitivity of 53.5% and a specificity of 69.3% as shown in table 4.8. The score was therefore considered to have inadequate overall performance as a screening tool.

The score however performed differently when applied to individual study sites (table 4.8) and a cut-off of 11.75 in Ethiopia had a sensitivity of 84.3%, a specificity of 61.5%, and an AUC of 0.77; while a cut-off of 10.25 in Nepal would reach a sensitivity and specificity of 69% and 42.4%, respectively, with an AUC of 0.57. Ethiopia and Yemen had similar ROC and AUC, while Nepal and Nigeria had flatter patterns with lower specificity and AUC. The ROC curves for each study site are shown in figure 4.2.

Figure 4.1. ROC curve for the generic score for all countries combined

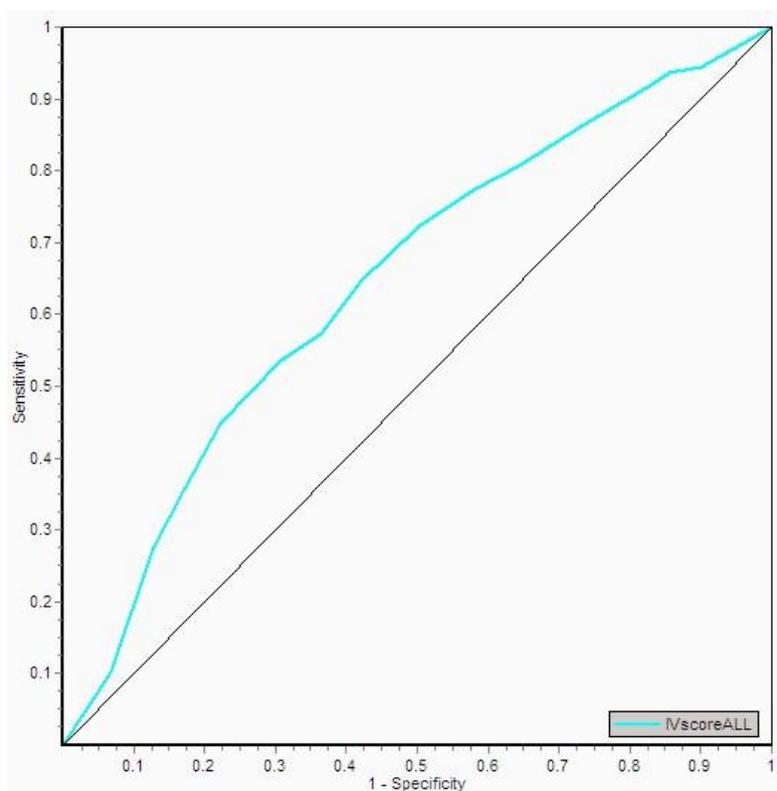
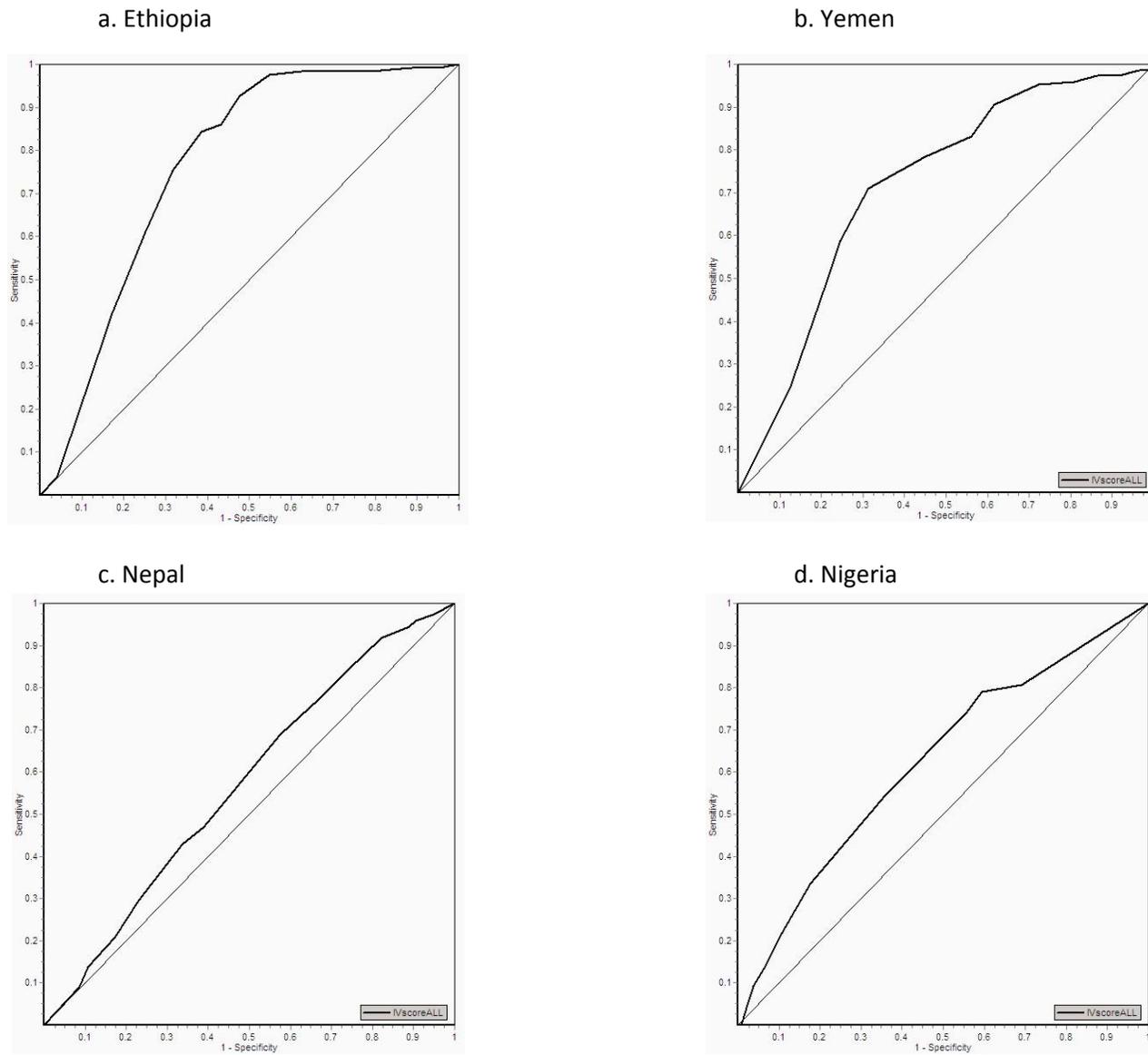


Table 4.8. ROC curve analysis for the generic score by study site

	N	Ideal cut-off	Sensitivity	Specificity	AUC
Ethiopia	500	11.75	84.3%	61.5%	0.77
Nepal	603	10.25	69%	42.4%	0.57
Nigeria	494	7.75	79%	40.5%	0.62
Yemen	598	12.25	71%	68.7%	0.72
All countries	2195	11.75	53.5%	69.3%	0.64

Figure 4.2. ROC curves for the generic score by study site: a. Ethiopia, b. Yemen, c. Nepal and d. Nigeria



### Country-specific scores

The country-specific scores followed the same approach as the generic score, but analysed each country separately to identify variables associated with high expenditure. Country-specific scores used the variables listed in table 4.6. The AUC of the scores ranged from 61% (Nepal) to 76% (Ethiopia), as shown in table 4.9. Similar to the generic score, Ethiopia and Yemen's country-specific scores performed better than Nigeria and Nepal's scores.

The best cut-off value selected by the software for Ethiopia was 51.25, which reached a sensitivity of 90.9% but a disappointing specificity of only 53.3%, with an AUC of 0.76. In contrast, a cut-off of 13 in Nepal reached a sensitivity and specificity of 57.4% and 59.1%, respectively, with an AUC of 0.61, which is only marginally higher than the performance of the generic score and too low for screening purposes.

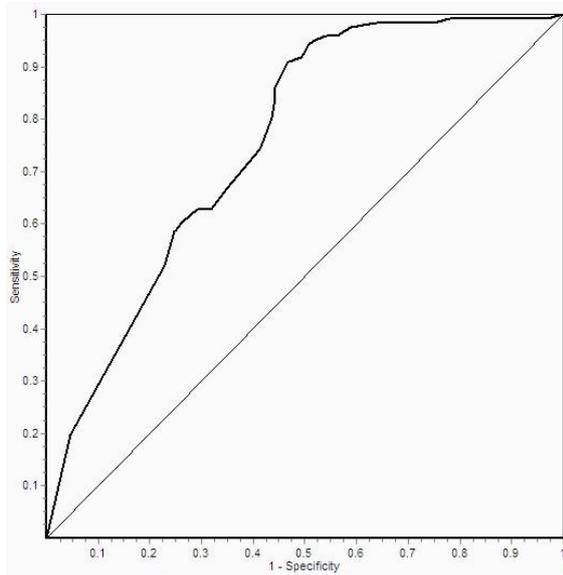
Ethiopia and Yemen had similar ROC curves and relatively high AUC values, while Nepal and Nigeria had flatter ROC curves, with lower specificity and AUC. The ROC curves for each study site are shown in figure 4.3.

Table 4.9. ROC curves analysis for site-specific score

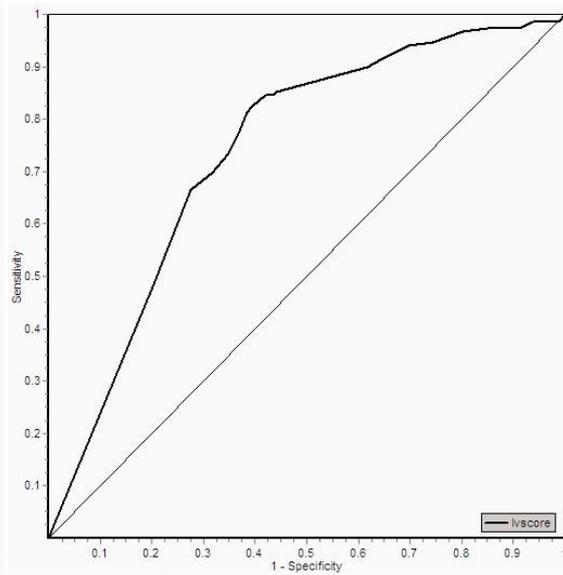
	N	Cut-off	Sensitivity	Specificity	AUC
Ethiopia	498	51.25	90.9%	53.3%	0.76
Nepal	606	13	57.4%	59.1%	0.61
Nigeria	494	4.3	62.2%	66.9%	0.66
Yemen	599	26	82.6%	60.4%	0.73

Figure 4.3. ROC curves for the site-specific scores: a. Ethiopia, b. Yemen, c. Nepal and d. Nigeria

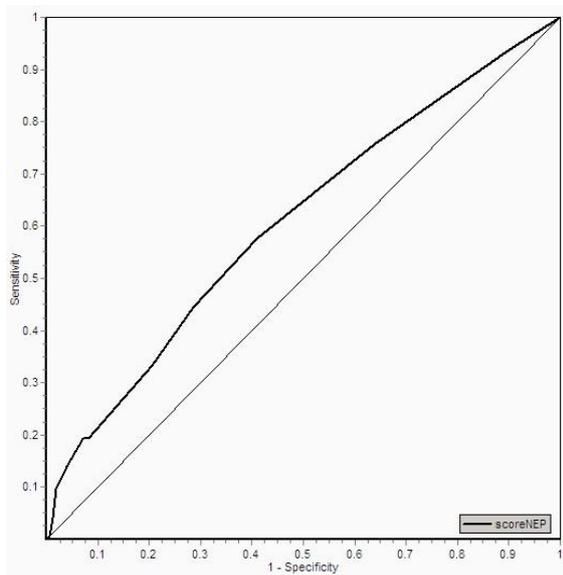
a. Ethiopia



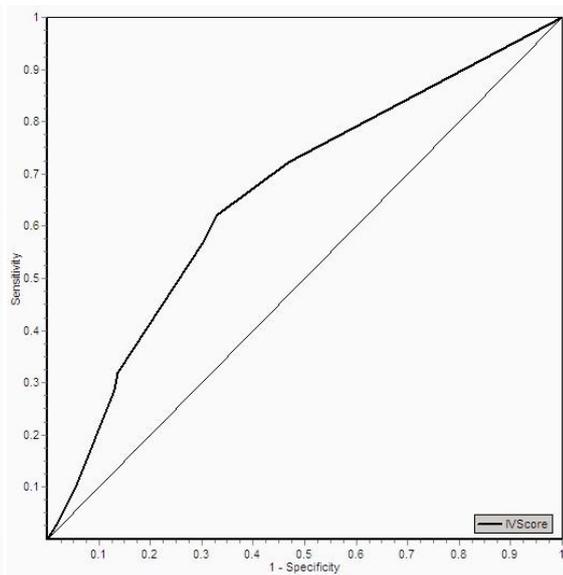
b. Yemen



c. Nepal



d. Nigeria



## Discussion

Financial considerations by patients play a significant part in limiting public access to formal TB diagnostic facilities and eventual anti-TB treatment. Low income and poverty are associated with delayed patient presentation to TB services, including in Ethiopia and Yemen (Bates et al. 2004b; Cambanis et al. 2005a; Cambanis et al. 2007; Storla et al. 2008) and economic poverty is associated with non attendance (Bates et al. 2004c) and patient drop out from diagnostic services (WHO 2005). Although research indicates that the costs associated with diagnosis are significant for low income populations and can prove prohibitive for the poorest patients (Squire et al. 1996; WHO 2005), there is little documentation of these expenses in several countries, and very few have employed comparable methodologies. There is also little information about the factors associated with high expenditure in resource-limited contexts and sectors of the population that could be at risk of high expenditure. This study thus set out to describe and classify the costs incurred by patients attending TB diagnostic centres in Ethiopia, Nepal, Nigeria and Yemen and to differentiate first and second day expenditure. Factors associated with high patient expenditure were identified in each country and findings were compared in order to identify common patterns across the study sites.

Participants in the study had characteristics common to most patients in LMIC. For example, more men than women attended TB diagnostic services (Ganapathy et al. 2008), with the exception of Nigeria where the number of male to female patients was comparable. In Nepal, Ethiopia and Yemen, over half of patients resided away from the town or city in which the clinic was located and a substantial number in Ethiopia and Yemen came from a rural area, suggesting that diagnostic services were not available in the proximity for most patients or, that patients may prefer to travel to places where they could be screened without being identified, for fear of stigma. A large majority of patients were accompanied to the health centre, and although most marked in Yemen, over 70% of patients were accompanied in Ethiopia and Nepal. Patients were mostly accompanied by a relative. The need for company may reflect the physical fragility of patients with chronic debilitating conditions and cultural norms, established gender roles and poverty, which constrains the free

movement of individuals. The fact that the vast majority of companions were relatives could arise from family solidarity in the study settings, where the extended family commonly forms part of the family unit, but could also point to fear of stigmatisation by non-family members. These patterns therefore are further explored in chapters 6 and 7 using qualitative methodologies.

The most important direct costs incurred by patients were clinic fees, transport and unspecified miscellaneous expenses. The relative importance of these varied for each country. In Yemen, transport costs constituted the greatest expense. This can probably be explained by the high number of patients self referring from rural areas and the long travel time from home to the clinic. Similarly in Ethiopia, transport costs accounted for the majority of expenditure, where a large number of patients travelled from the countryside or another town. In Nepal, clinic fees and unspecified costs were a greater consideration for patients than transport costs. Here, patients travelled for the shortest amount of time and few came from the countryside, while in Nigeria, unspecified miscellaneous expenses were more considerable than transport and clinic fees, as the majority of patients lived in Abuja. These considerations suggest that although participating centres seemed to be fairly homogeneous, they served populations that were heterogeneous, which may explain the variations in the risk factors identified. The composition of the unspecified miscellaneous costs is further explored in the qualitative studies.

Across the study settings, expenditure on food and overnight accommodation was low and infrequent, as many patients relied on relatives that resided in the town of the study or could not afford paid accommodation, raising the question whether a single day diagnosis might have the unintended consequence of reducing the exposure of relatives to potentially infective adults.

Whether relatives with brief but close encounters are at risk of infection is poorly documented in the literature.

Public health services often develop consultation charging policies and payment for diagnostic tests.

Clinic fees might include several charges including an admission fee to the centre (often a

registration card), consultation fees to be seen by a junior or senior health practitioner, sputum tests, X-rays, blood tests to screen for other diseases and HIV testing. There are indications in later studies (chapters 6 and 7), that charging policies were not transparent in some health settings and that some centres' staff often requested underhand payments to accelerate the processing of specimens, to be seen earlier and to gain other favours which may explain differences within a study site. Although some of the study settings reimbursed the diagnostic costs of patients with TB, this group represents the minority, as typically only 10-20% of all patients are diagnosed as having TB. This is likely to be confusing to the patient, as only a minority would qualify for reimbursement of the payments made, while the majority would be given alternative diagnoses without reimbursement.

Charges incurred by patients in the study also varied across the settings. The median cost in US dollars of attending the clinic for 2 days was highest in Yemen, followed by Nepal, Nigeria and Ethiopia. However, a mechanical conversion to US dollars does not provide costs in real terms. Costs in Yemen appear higher, but as Yemen is arguably the least poor country of the four, patients may be relatively better able to afford the cost of diagnosis. According to the Multidimensional Poverty Index (Alkire and Santos 2010) the countries participating in the study when ranked from poorest to least poor are Ethiopia, followed by Nepal, Nigeria and Yemen.

Median first and second day costs associated with clinic attendance were comparable, with the exception of Yemen, where patients anticipated spending less on the second day due to reduced transport costs. The difference in Yemen could be explained by the location of the centre on a hill without public transport. Most patients arriving at the foot of the hill then pay a taxi for the relatively short distance to take them to the centre. On the second day most patients walk to save these costs. The centre staff was aware of the situation and had implemented a shuttle bus in the past. However this was discontinued due to lack of funds. Neither were second day costs

augmented by arrangements for overnight accommodation, as comparatively few patients used paid accommodation, planning instead to stay at home or with family.

A same-day diagnosis microscopy scheme could lead to savings of approximately 50% for the patients that had positive smears on the first day of consultation in centres that continued to use three smears, and potentially 50% of the costs for *all* patients if the diagnosis were based on two smear examinations, thus avoiding sustaining second day expenses. The savings brought about by a frontloaded scheme would not be substantial unless specimens for tests were collected, processed and reported the same day and clinical decisions could be taken by staff working in the afternoon. Although not documented in the survey, indirect costs such as opportunity costs constitute a major part of patients' outgoings as documented in chapters 6 and 7. Opportunity costs tend to be higher for poor people who for the most part work in the informal sector and are vulnerable to loss of income or dismissal from work (Bates et al. 2004b; WHO 2005). In countries with high HIV seroprevalence this vulnerability is heightened for TB suspects infected with HIV (WHO 2005).

The direct costs described here therefore represent only a proportion of the economic barriers faced by TB suspects. Furthermore, since a large proportion of symptomatic adults are known not to attend diagnostic centres, it can be assumed that those remaining in the community have fewer financial and social resources at their disposal; including perhaps the option of staying with family or friends in the city.

The case control analysis identified similarities and differences between countries in the patient characteristics significantly associated with higher expenditure. The main patient characteristics associated with high costs *across* the study sites at the univariate level were being older than 50 years, residing in a rural areas or other towns, illiteracy, having no or little formal education, being accompanied to the clinic, being out of work at the time of consultation and having certain occupations. The characteristics that remained independently associated with high expenditure after logistic regression were being accompanied to the clinic and residing in a rural area or other

town. It is clear that patients who attend the clinic with one or more companions are at risk of sustaining heightened costs; as are those that live outside the town or city in which the clinic is located. Patients from rural areas had been found to have higher expenditure in a previous study in Nepal and Ethiopia (Ramsay et al. 2010). It seems that older age, low education and low income are likely to be confounding factors for rural residency.

The scores developed to identify patients at risk of high expenditure attained similar performance, whether the generic or country-specific score was utilised. In Ethiopia and Yemen, the scores achieved a reasonable sensitivity and specificity, with an AUC of over 70%. In Nepal and Nigeria, however, the scores performed poorly for practical application. The risk factors for higher expenditure in Ethiopia and Yemen were similar, which perhaps provides a partial explanation for the higher performance of the scores. The scores therefore show potential for use as screening tools, but need to be further refined, by being tailored to suit the demographic profile of different settings.

This analysis, however, has some limitations, beginning with the sampling strategy, which carried a risk of selection bias. Participants were recruited consecutively, rather than randomly, as this suited the objectives of the larger clinical trial. Patients arriving at the beginning of the day might have had different characteristics from those arriving later. We can hypothesise that the former might have resided more locally, or conversely, have travelled the previous day from afar and stayed overnight. Patients arriving early might have been better prepared. Next, second day costs were calculated according to patients' predicted expenses, rather than the actual costs incurred. Moreover, all costs were self-reported, rather than observed by investigators. Actual and predicted expenditure might have been expressed differently by different subgroups of the population and different cultures, as mediated by established social hierarchies, gender roles, economic standing and the distribution of power, to name but a few modifiers. For example, costs which might be overstated by patients in one setting in the hope of financial remuneration might be underreported in another out of

individual pride. Women who do not have access to household finances might also be unaware of the full cost of attendance. Calculation of costs as a proportion of individual income would have provided a more complete picture of the economic burden for the individual and their family (Kemp et al. 2007; Simwaka et al. 2007; Yan et al. 2007), however including the many variables involved in these calculations was not possible within the confines of a short addition to a large survey and asking participants to disclose their income was considered unreliable.

This analysis demonstrates that the costs for diagnosis sustained by patients were substantial, of which a large component were for clinic fees and transport costs. In addition, a large proportion of patient expenditure was on items that were not anticipated or identified by the researchers and these are explored in later, linked studies. Defined population groups - in this case rural residents attending with company – therefore are at greater risk of experiencing higher costs. Concerns over user fees, travel expenses and lost earning time or opportunity have been identified by others as important characteristics hindering access to formal diagnostic services for TB (Foster 1999) and this is not solely the case for TB; it also applies to other acute and chronic diseases (Lönnroth et al. 2010b) such as malaria and HIV (Bates et al. 2004c).

Much is known about economic barriers to successful treatment and the reduced chances of cure of poor patients compared with the non-poor (Lönnroth et al. 2010b). Our findings also suggest that there is potential to undertake a socio-economic assessment of patients when they present to diagnostic centres to identify patients at risk of high expenditure and so channel additional support to those most at risk of dropping out and those less likely to have a successful treatment outcome. The tool could also be adapted for use at treatment registration. Losing smear positive patients to return to the community increases the disease burden and carries resource implications for the local economy and health services, quite apart from the health implications for the individual. Identifying population groups at risk of higher expenditure therefore could contribute to building a profile of

patients at risk of defaulting. If health services had the training and resources to respond to their needs, this might be one method of improving patient adherence at diagnosis.

The costs in this study were assessed at the time of attendance at TB diagnostic services, yet it is well-established that in many settings individuals with cough are never seen by the health centres (Dye et al. 1998b). Of the 8.8 million incident cases estimated by the WHO, only 5.7 million (65% of new and recurrent cases) are actually reported (WHO, 2011b) and the rest are missed. Thus access is still a major problem and we have only identified the costs of people who reached services.

Further research is thus needed to take one step back earlier into the process and identify the characteristics of individuals not attending diagnostic centres. This would require house to house surveys to identify symptomatic individuals and explore barriers for access. Symptomatic adults remaining in the community are likely to live in rural areas with less access to healthcare, have fewer resources, be less educated and have less awareness of TB (Bates et al. 2004b).

TB is a disease of poverty affecting populations with limited resources and limited access to health services. Moreover, the onset of disease, as with many other major diseases, further aggravates poverty for the individual, who enters a lengthy period of expenditure on healthcare and loss of productivity (Benatar 2010). In addition to measures to tackle the root causes of poverty leading to disease vulnerability (Benatar 2010), financial barriers could be alleviated at the point of care through the provision of free diagnostic services, decentralisation of health services, the provision of transport for remote populations and/or mobilisation of services to remote communities (WHO 2005). Local scores can be developed to identify patients at risk of high expenditure to inform schemes that provide financial support and incentives for high risk groups, such as the offer of free healthcare to contacts and family members of confirmed TB cases.

This study was only concerned with direct costs. Further studies seeking to ascertain indirect costs incurred by patients, such as loss of income would be informative. In addition, economic poverty constitutes only one aspect of the access barriers faced by symptomatic adults in low income

countries. The next chapters therefore explore other aspects such as education, behaviour, attitude and knowledge, gender and residence, which hinder access to diagnostic services.

## Chapter 5

### **Beyond cost: exploring non-financial barriers and enablers to accessing TB diagnosis and treatment in Ethiopia and Yemen**

*“Things worth telling - take time”*

— Nicholas Denmon

#### **Introduction**

Having established the considerable financial costs involved with attending TB diagnostic services, a second cross sectional survey was conducted to examine non-financial factors impeding patients' attendance and completion of diagnosis in Yemen and Ethiopia, to establish a baseline of the most prevalent barriers and to inform further qualitative studies. Factors known to be associated with patient delay in presenting to formal health services for diagnosis include health systems' barriers such as poor access to health services and consultation with informal, private or general health service providers; geographical factors such as rural residency; social factors such as stigma, and structural issues such as poverty, vulnerability, immigration, gender and low health education or awareness (Cambanis et al. 2005a; Cambanis et al. 2007; Demissie et al. 2002; Sagbakken et al. 2008a; Sanou et al. 2004a; Storla et al. 2008). Many of these barriers are common to patients undertaking treatment (Munro et al. 2007). Few studies, however, have compared the reasons for patients defaulting *during* diagnosis in different settings or the enablers that support patients to complete the process.

This survey therefore set out to describe the characteristics of individuals attending the services and their companions, their health seeking behaviour before attending the TB diagnostic centres, their attitude towards and knowledge of TB and their perception of service quality and recourse to social support networks, as factors that could hinder completion of the diagnostic process.

These factors were examined in two contrasting settings with high TB incidence, Ethiopia and Yemen, to identify different and common barriers that could apply to many populations. Ethiopia is a country with a predominantly rural, low-income population, a plethora of linguistic and cultural groups and an orthodox Christian majority and Yemen is a country with a traditional Muslim Arab population in the North and a less conservative population in the formerly socialist South, also with a large rural population clustered in village settlements and cities isolated by geographical and historical divides.

## **Methodology**

The study comprised two cross sectional surveys conducted among adults > 18 years old with a complaint of chronic cough of more than 2 weeks duration, attending two TB diagnostic services in Ethiopia (Awassa and Bushullo Major Health Centres) and the NTI in Sana'a, Yemen. These were the same centres in Ethiopia and Yemen described in Chapter 4. The studies took place a few months after the cost surveys had been completed and therefore participants' characteristics are similar, but not identical, to those described in the previous chapter. Patients were selected at the time of their first attendance for diagnosis and interviewed to investigate their knowledge of diagnostic services, perception of service quality, understanding of the disease and previous health-seeking behaviour. Information was gathered using structured questionnaires (Appendix 6) that included questions with a core statement and a list of potential answers. Interviews lasted approximately 30 minutes and were held in a separate room (the health education room), where patients could be interviewed apart from those waiting for examination. For some questions, only those responses spontaneously mentioned by the interviewee were recorded, while for others, participants were asked to indicate whether the statement was correct, incorrect or they did not know the answer. Variables were selected to give an indication of the patients' socio-economic background, using indicators such as educational level, living conditions and occupation, and factors associated with defaulting from the diagnostic process or treatment registration. A follow up interview was conducted with patients

submitting samples for smear microscopy the second day, to explore their experience of diagnosis. Patients were asked to indicate whether they understood the diagnosis and whether they would communicate the diagnosis to peers and relatives, and enablers and factors potentially associated with treatment adherence were identified.

Questionnaires were pre-tested by the local investigators and reviewed to develop a single questionnaire that could be applied to both countries. Only questions regarding co-infection with HIV were not systematically completed in Yemen, as they were deemed too sensitive and potentially offensive to the local population.

#### *Patient selection, sampling frame and interviews*

Patients in both countries were screened after registration with the diagnostic services. Any adult with cough of 2 or more weeks' duration who had attended during regular service hours was deemed eligible to participate. Potential participants were informed of the purpose of the interview and invited to participate after receiving information about the purpose of the study. Face-to-face interviews were conducted after obtaining informed written consent. Patients were reassured that the interview was confidential and that they could withdraw their consent at any time. Patients completing smear microscopy on the second day were invited to attend a follow-up interview and thus the majority of patients were interviewed on the first and second day of attendance for diagnosis. Although for the majority of patients the second interview took place on the subsequent working day, some patients may have decided to attend a few days later and thus their second interview may have taken place a few days later. Both interviews were held before patients received health education. Participating health centres were alternating the standard (spot-morning-spot) and frontloaded (spot-spot-morning) schemes for the collection of specimens for smear microscopy, as described in chapter 4. The rotation was activated on a monthly or bi-monthly basis, according to a pre-arranged timetable for concurrent studies. However, at the time of the study, all patients were being asked to provide three specimens over two consecutive days and

therefore were expected to attend the health service for a minimum of two days. The purpose of implementing the schemes was to obtain baseline information for the planned implementation of the same-day diagnostic scheme at a later date, in which only two smears were to be examined and the diagnosis would have been completed in a single day. As all patients attended the centres for the same number of days, the views of the patients under the two schemes are not presented separately, as patients are unlikely to have experienced any discernible difference between the two approaches.

The recruitment pathway for the survey interviews is described in Appendix 12. After registration with the health centre, patients waited in a common area to attend a first consultation. If the history and examination by the clinician suggested that the patients could have TB, the doctor requested sputum smear microscopy examinations and the patients' details were entered into a logbook (Appendix 13). For logistical reasons, an average of six patients was selected per day for interview (30 per week). Patients were selected from the logbook using systematic sampling and the sampling interval was established to ensure enrolment of about 6 patients per day. Some flexibility however was allowed due to fluctuating patient numbers. In Ethiopia, for example, the clinic was less busy on market days and on Fridays for the Muslim call to prayers, and busier after the weekend break. Patients enrolled from each site were interviewed face to face using structured questionnaires.

#### *Sample size and analysis*

Sample size was calculated to estimate the prevalence of the parameters of interest. Given that a large number of variables were included, it was decided to calculate the sample size assuming the parameters had a prevalence of 50% (the prevalence that requires the largest sample size) and to attain a precision of +/- 5%. A sample size of at least 500 patients was considered sufficient to satisfy these two conditions.

Completed questionnaires were checked to identify missing data and clarify entries that were unclear or required translation. Data were entered into *Epi-Info* (CDC 2008) and databases were checked for typing errors or inconsistencies.

The analysis included summary statistics of all variables, using means or medians and standard deviations or ranges for continuous variables and proportions for categorical variables. Means and medians were compared using Student's T tests or non parametrical tests, respectively. Differences in proportions between the countries and among the participants' categories were compared using Chi-squared tests or Fisher exact tests, as suitable. P values less than 0.05 were considered statistically significant.

#### *The research team*

In Ethiopia, one social worker was employed at each of the two sites to carry out the interviews. Both assistants were trained nurses; one was studying for a degree in social sciences and the other for a degree in nursing. The latter had been employed by the researchers on previous studies in social medicine, tracing defaulters and discussing reasons for defaulting. A social scientist with a background in community health was employed to lead data collection locally and the team was managed by a local co-ordinator with several years' experience of working with the regional NTP.

In Yemen, interviews were led by a social scientist with a degree in social sciences (University of Sana'a), programme experience and a lectureship in the School of Sociology. He led a team of three interviewers employed for the project with backgrounds in pharmacology (1), general health studies (1) and nursing (1).

In both countries, the research team was supervised by the partner co-investigators.

Ethical approval for the study was obtained from LSTM and the participating centres, as described in the general methods chapter 3.

## Results

### Characteristics of participants

A total of 609 participants were enrolled in Ethiopia, with a mean (SD) age of 33.8 (14.8) years and 55.8% (340) were male, as shown in table 5.1. A further 497 participants were enrolled in Yemen, with a mean (SD) age of 42.8 (14.8) years ( $p < 0.001$ ) and 50.8% (251) were male ( $p = 0.054$ ). Nearly all participants enrolled in Ethiopia had been born in the country, while 6.8% of participants in Yemen were foreigners, mostly from neighbouring Somalia.

A large proportion of the participants resided in the same town (49.9% and 49.7%, in Ethiopia and Yemen, respectively), with a higher proportion residing in rural areas in Yemen (46.7%) than in Ethiopia (23.8%,  $p < 0.001$ ). A high proportion of participants were unable to read (40% in Ethiopia and 57.5% in Yemen,  $p < 0.001$ ), with only a minority attaining higher education.

Participants had a wide range of occupations, with more farmers enrolled in Ethiopia than Yemen and more housewives and civil servants enrolled in Yemen ( $p < 0.001$ ). Participants in both countries resided in large families, although families in Yemen were larger (median 8 residents per household) than in Ethiopia (median 5 residents).

**Table 5.1 Demographic characteristics of the participants**

		<b>Ethiopia N = 609 (%)</b>	<b>Yemen N= 497 (%)</b>	<b>p</b>
<b>Age</b>	Mean (SD), years	33.8 (14.8)	42.8 (18.4)	<0.001
	Range, years	18-87	16-90	
<b>Sex</b>	Male	340 (55.8)	251 (50.8)	0.054
	Female	269 (44.2)	243 (49.2)	
<b>Place of birth</b>	Same country	605 (99.7)	456 (93.2)	<0.001
	Another country	2 (0.3)	34 (6.8)	
<b>Residency</b>	Study town	304 (49.9)	247 (49.7)	<0.001
	Other town	160 (26.3)	18 (3.6)	
	Rural	145 (23.8)	232 (46.7)	
<b>Literacy</b>	Can read	365 (59.9)	211 (42.5)	<0.001
	Unable to read	244 (40.1)	286 (57.5)	
<b>Education</b>	None	256 (42.0)	302 (60.9)	<0.001
	Primary incomplete	132 (21.7)	77 (15.5)	
	Primary complete	60 (9.9)	33 (6.7)	
	Secondary	84 (13.8)	50 (10.1)	
	Higher education	77 (12.6)	34 (6.9)	
<b>Occupation</b>	Farmer	155 (25.7)	47 (10.1)	<0.001
	Student	73 (12.1)	29 (6.3)	
	Housewife	138 (22.8)	182 (39.2)	
	Daily labourer	92 (15.2)	85 (18.3)	
	Merchant	37 (6.1)	7 (1.5)	
	Civil service	53 (8.8)	64 (13.8)	
	Other	56 (9.3)	50 (10.8)	
	Median [range]	5 [0-17]	8 [0-50]	
<b>Number of residents</b>				<0.001

Similar to the surveys described in chapter 4, a high proportion of patients were accompanied when attending the services. There were, however, differences in the patterns of companionship between the two study centres. For example, the proportion of patients with company was much higher in Yemen than in Ethiopia ( $p < 0.001$ ), and females were more likely to be accompanied than males ( $p < 0.001$  in both countries, as shown in table 5.2. Gender differences were more marked in Yemen, where only 12 (5%) of females attended without company. Similarly, the majority of accompanied Ethiopian patients attended with one other person (73.6%), while in Yemen 55.5% of accompanied persons attended with two or more companions ( $p < 0.001$ ) and one person attended with 9 other persons. Although most companions were relatives, the accompanying relative varied, as in Ethiopia the most frequent companion was the spouse/partner, while in Yemen the most frequent

companion was a relative other than the spouse. One characteristic common to both countries is that very few patients attended accompanied by neighbours or friends.

**Table 5.2 Characteristics of individuals accompanying patients by country**

		<b>Ethiopia</b>	<b>Yemen</b>	<b>p</b>
		<b>N = 609 (%)</b>	<b>N= 497 (%)</b>	
<b>Presence of companions</b>	Alone	261 (42.9)	78 (15.7)	< 0.001
	Accompanied	348 (57.1)	418 (84.3)	
<b>Males</b>	Alone	170 (50.0)	65 (25.9)	< 0.001
	Accompanied	170 (50.0)	186 (44.7)	
<b>Females</b>	Alone	91 (33.8)	12 (5.0)	< 0.001
	Accompanied	178 (66.2)	230 (95.0)	
<b>Number of companions</b>	1	259 (73.6)	212 (44.5)	< 0.001
	2	70 (19.9)	143 (30.0)	
	3	15 (4.3)	54 (11.3)	
	4	7 (2.0)	11 (2.3)	
	≥ 5	1 (0.3)	5 (1)	
<b>Accompanying person</b>	Spouse/partner	197 (56.4)	49 (11.0)	< 0.001
	Other relative	123 (35.2)	341 (76.6)	
	Friend	22 (6.3)	12 (2.7)	
	Neighbour	4 (1.1)	6 (1.3)	
	Not stated	3 (0.9)	0 (0)	

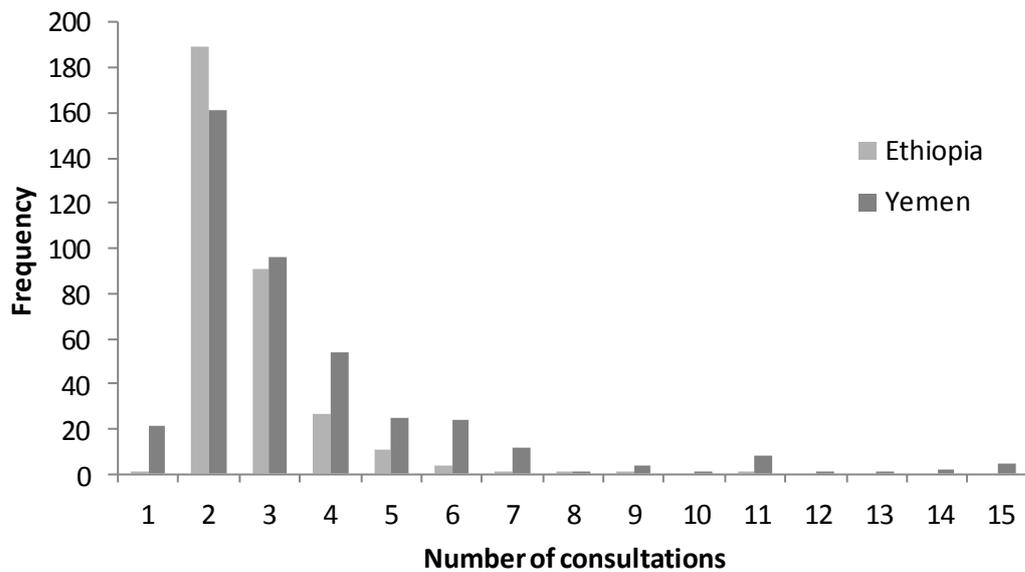
Most patients had sought help elsewhere before attending the study centres. This was more frequent in Yemen, where up to 81% had attended other centres (Table 5.3). Patients had made a median of one (Ethiopia) or two (Yemen) visits to other centres, with a maximum of 10 and 20 visits, respectively, as shown in Figure 5.1. Most patients had consulted conventional health professionals, with a high proportion in both countries consulting private practitioners.

**Table 5.3. Health seeking behaviour of participants before consulting the study centres**

		<b>Ethiopia</b>	<b>Yemen</b>	<b>p</b>
		<b>N = 609 (%)</b>	<b>N= 497 (%)</b>	
<b>Sought help elsewhere</b>	Yes	342 (56.2)	395 (80.9)	< 0.001
	No	267 (43.8)	93 (19.1)	
<b>N. of consultations</b>	Median [range]	1 [0-10]	2 [0-20]	
<b>Service consulted*</b>	Traditional healer	9 (2.7)	31 (7.7)	
	Pharmacy/over the counter	23 (6.8)	82 (20.3)	
	Self treated	1 (0.3)	16 (4.0)	
	Primary Health centre	125 (36.9)	21 (5.2)	
	Chest hospital	3 (0.9)	24 (6.0)	
	Public hospital	40 (11.9)	177 (43.2)	
	Private practitioner	184 (54.4)	255 (62.2)	

\* Multiple answers were allowed

**Figure 5.1. Number of consultations to other health providers before attending the study centres.**



#### **Participants' attitudes towards and knowledge of TB**

Participants were asked whether they had heard of TB and knew how TB was transmitted. Patients were asked to consider a series of statements about TB transmission and to state whether they were correct or incorrect or if they did not know the answer. Eighty-seven patients in Ethiopia and 100 in Yemen, who indicated they had formerly received treatment for TB were excluded from this analysis, as they would have had substantially more contact with the health services and distorted the response patterns.

Of the remaining participants, 375 (72.4%) of 518 patients in Ethiopia and 316 (82.1%) of 384 in Yemen indicated they had heard of TB before ( $p < 0.01$ ). Many patients, however, provided erroneous answers about the way TB is transmitted and the pattern of these misconceptions was fairly similar in both countries, as shown in Table 5.4. A minority indicated TB could be inherited (15% and 21.4% in Ethiopia and Yemen, respectively); a higher proportion believed it could be transmitted from animals (44.8% and 66.6%), other persons with diarrhoea (42.5% and 58.1%, respectively) or, most frequently, from cold air (84.7 and 84.4%). Similarly, the majority of patients thought TB and HIV were not associated with each other (66.6% and 89.1%) and a large proportion were unaware that TB treatment is free of charge (57.9% and 49.3%, respectively).

The majority of participants, however, knew TB could be transmitted by a person with TB (81.9% and 71.3%, respectively) and that TB is a treatable disease (82.9% and 71.3%).

**Tables 5.4. Participants' knowledge of tuberculosis**

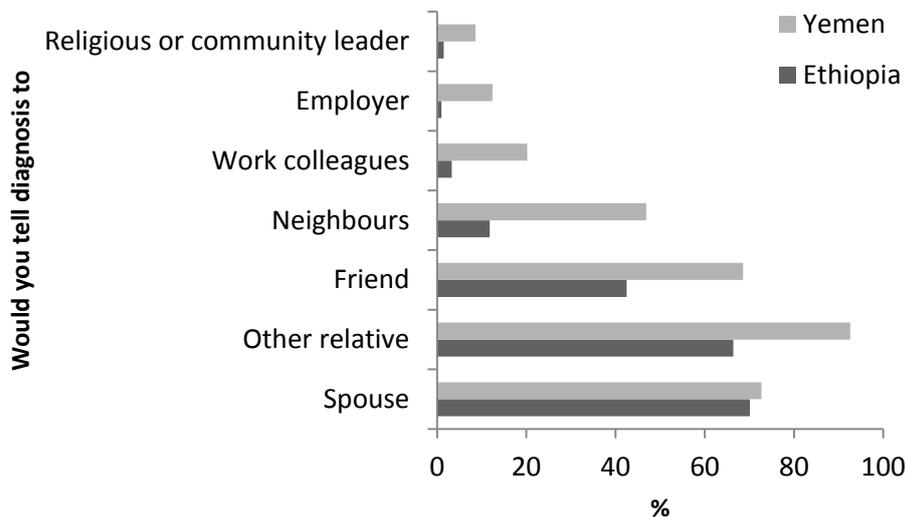
			<b>Ethiopia</b> <b>N = 609 (%)</b>	<b>Yemen</b> <b>N= 497 (%)</b>	<b>p</b>
<b>Previous TB Treatment</b>	Yes		87 (14.4)	100 (20.3)	< 0.05
	No		518 (85.6)	393 (79.7)	
<b>Had previously heard of TB (previously treated excluded)</b>	Yes		375 (72.4)	316 (82.1)	<0.01
	No		143 (27.6)	68 (17.7)	
<b>Believes TB is inherited</b>	Yes		77 (15.0)	80 (21.4)	< 0.05
	No		265 (51.6)	191 (51.2)	
	DN		172 (33.5)	102 (27.3)	
<b>Can catch it from exposure to (Correct answer underlined)</b>	Diarrhoea	<u>No</u>	220 (42.5)	216 (58.1)	<0.001
		Y/DN	298 (57.6)	156 (41.9)	
	Cold	<u>No</u>	79 (15.3)	58 (15.6)	0.9
		Y/DN	439 (84.7)	314 (84.4)	
	Animals	<u>No</u>	187 (36.1)	145 (39.0)	<0.03
		Y/DN	232 (44.8)	248 (66.6)	
	TB	<u>Yes</u>	424 (81.9)	266 (71.3)	<0.001
		No	94 (18.1)	117 (28.7)	
<b>TB can be treated</b>		<u>Yes</u>	426 (82.9)	297 (80.7)	0.4
		N/DN	88 (17.1)	71 (19.3)	
<b>TB and HIV are linked</b>		<u>Yes</u>	172 (33.3)	40 (10.9)	<0.001
		N/DN	344 (66.6)	326 (89.1)	
<b>TB can be prevented</b>		<u>Yes</u>	385 (74.3)	298 (80.1)	0.053
		N/DN	133 (25.7)	74 (19.7)	
<b>Patients pay for TB treatment</b>		<u>No</u>	218 (42.1)	188 (50.7)	<0.001
		Y/DN	300 (57.9)	183 (49.3)	

\* Y = Yes, N = No, DN = Does not know.

#### *Willingness to disclose diagnosis*

Most participants indicated they would be prepared to disclose their diagnosis of TB to other persons (519 [85.5%] in Ethiopia and 404 [82.6%] in Yemen). However when asked to name the persons to whom they would disclose the diagnosis, patients indicated they would inform their spouses (70.1% and 72.7% in Ethiopia and Yemen, respectively) or a relative (66.4% and 92.6%), but very few would inform their employer, work colleagues, religious or community leaders, as shown in Figure 5.2. These patterns were similar in both countries, suggesting that patients worry about

incurring negative reactions from individuals outside their family and suggest that TB carries a high degree of stigma in these populations.



**Figure 5.2. Individuals to whom patients would be prepared to disclose a diagnosis of TB**

*Women’s access to healthcare*

Participants in both countries indicated women had the same access to healthcare as men, and in Ethiopia few (11.6%) believed that women faced difficulties accessing healthcare, as shown in table 5.5. However 57% of respondents in Yemen indicated women found it more difficult to access healthcare. Of these, 91.1% volunteered that women had to request permission from their husbands to attend health facilities, and 91.4% that women could not travel alone to the centres. A high proportion (37.6%) also indicated women’s attendance was impeded by having to look after their immediate or extended family members and a lack of authority to access household funds.

**Tables 5.5. Perception of reasons why women face difficulties accessing health care facilities**

Believes that women		Ethiopia N = 609 (%)	Yemen N= 497 (%)	P
<b>Have same access to health care as men</b>	Yes	479 (79.0)	419 (84)	< 0.001
	No	57 (9.4)	66 (13.4)	
	DN*	70 (11.6)	7 (1.4)	
<b>Face difficulties accessing health care</b>	Yes	70 (11.6)	278 (57.2)	< 0.001
	No	438 (72.4)	203 (41.8)	
	DN	97 (16.0)	5 (1.0)	
<b>Reason for above:</b>				
Need to ask their husband's permission	Yes	15 (22.7)	275 (91.1)	< 0.001
	No	51 (77.3)	27 (8.9)	
Cannot travel alone to health services	Yes	9 (13.6)	276 (91.4)	< 0.001
	No	57 (86.4)	26 (8.6)	
Need to care for other relatives	Yes	32 (48.5)	111 (37.6)	> 0.1
	No	34 (51.5)	184 (62.4)	
Cannot use household funds	Yes	21 (31.8)	71 (24.2)	> 0.1
	No	45 (68.2)	222 (75.8)	

\* DN = Does not know

### **Second day interview**

A total of 481 (79.2%) and 446 (91.6%) patients completing the first day interview agreed to be interviewed the second day in Ethiopia and Yemen, respectively. Of these, 264 patients (142 in Ethiopia and 122 in Yemen) indicated they had been told they had TB. The most frequent reason for some patients missing the second interview was not attending the service the next day or leaving the premises without being interviewed (106 in Ethiopia and 16 in Yemen). Remarkably few patients refused to be interviewed (4 in Ethiopia and 9 in Yemen).

### *Experience of diagnostic services*

The majority of patients indicated they were satisfied or very satisfied with their experience of the diagnostic services, the standard of service and the waiting times at the clinic (satisfied/very satisfied, 465 (97%) in Ethiopia and 399 (89%) in Yemen). Although most patients indicated they were satisfied with the attitude of staff, a higher proportion of patients in Ethiopia indicated they were satisfied (89%), as opposed to very satisfied (4.2%); while the majority of patients in Yemen indicated they were very satisfied (50.5%), as opposed to being satisfied (44.1%,  $p < 0.001$ ). A similar pattern was observed in response to satisfaction with the information received, as most patients in

Ethiopia indicated they were satisfied (80.8%) and very few were very satisfied (2.2%), while 47% of patients in Yemen were satisfied and 33.7% said they were very satisfied.

Despite expressing a high level of satisfaction, most patients in Ethiopia (411, 93.6%) felt they had not had time to ask questions of the medical staff and 48% indicated they did not know what disease they had been diagnosed with. This contrasted with Yemen, where 93.7% of participants indicated they had asked all the questions they had in mind, although 15.7% still said they did not know the disease they had been diagnosed with.

### *Sources of support*

Patients in Ethiopia indicated that the main source of support (financial, transport and food) was their spouse; however only 155 (32.2%) indicated their partner had provided financial support and lower proportions received help for transport and food. Very few patients indicated they had received financial help from other relatives, friends or members of the public. Patients in Yemen indicated that the main source of support (financial, transport and food) was a relative other than the spouse, and a much higher proportion than in Ethiopia indicated they had received financial (65.7%), transport (61.9%) and food (58.7%) support from these relatives. Similar to Ethiopia however, very few patients had received help from individuals outside the family.

**Tables 5.6. Sources of financial, transport and food support of patients in Ethiopia and Yemen.**

		<b>Ethiopia N = 481 (%)</b>	<b>Yemen, N= 446 (%)</b>
<b>Financial help received from</b>	Partner	155 (32.2)	54 (12.1)
	Relative	57 (11.8)	275 (65.7)
	Friend	10 (2)	17 (3.8)
	Other person	1 (0.2)	1 (0.2)
<b>Transport help received from</b>	Partner	119 (24.7)	49 (11)
	Relative	45 (9.3)	276 (61.9)
	Friend	9 (1.9)	20 (4.5)
	Other person	1 (0.2)	1 (0.2)
<b>Food help received from</b>	Partner	90 (18.7)	47 (10.5)
	Relative	36 (7.4)	262 (58.7)
	Friend	6 (1.2)	16 (3.6)
	Other person	0	1 (0.2)

### *Communication and understanding of diagnosis*

The doctors of patients participating in the study were asked to make a record of the diagnosis given, in order to confirm whether the answers provided by the participants corresponded to the recorded diagnosis. Among the 142 participants in Ethiopia who indicated they had been told they had TB, only 110 (77.5%) had been diagnosed as having TB and 32 (22.5%) had other diagnoses, as shown in table 5.7. Furthermore, 11 patients who said they did not have TB had a diagnosis of TB written in their records. Similarly, among the 120 patients in Yemen who reported having TB, only 81 (67.5%) had a recorded diagnosis of TB and 39 (32.5%) had other diagnoses. In addition, 13 patients who reported they did not have TB had a recorded diagnosis of TB. These findings demonstrate that information obtained from patients about their diagnosis can be unreliable, reflecting problems in doctor-patient communication or the reluctance of the patients to disclose their diagnosis to the interviewers.

**Table 5.7. Agreement between the diagnosis reported by the patient and the doctor.**

	Doctor diagnosis	Patient understanding of diagnosis			
		TB (%)	Not TB (%)	DN (%)	TOTAL (%)
Ethiopia	TB	110 (77.5)	1 (0.9)	10 (4.2)	121 (24.5)
	Not TB	32 (22.5)	114 (99.1)	227 (95.8)	373 (75.5)
Yemen	TB	81 (67.5)	9 (3.4)	4 (5.6)	94 (20.6)
	Not TB	39 (32.5)	255 (96.6)	68 (94.4)	362 (79.4)

### **Discussion**

The cross sectional surveys presented here provide information on the knowledge and perceptions of TB in Yemen and Ethiopia and complement the findings presented in the previous chapter. The surveys were conducted in the same centres and participants had similar characteristics, with some minor differences which are discussed later on.

The focus of these surveys differed from the cost analysis by exploring participants' understanding of the causes of TB and its methods of transmission, health seeking behaviour before attending the centres, understanding of their diagnosis and readiness to disclose the diagnosis to relatives and peers.

Quantitative surveys with closed and multiple choice questions are designed to elucidate frequencies of a range of anticipated responses and are therefore unable to elicit views falling substantially outside the answers selected by the researchers. Despite this limitation, they are efficient in terms of time and resources and can be a valuable foundation for more flexible approaches, such as the qualitative studies presented in chapters 6 and 7, which allow exploration of these issues in more depth but require more time and a good insight into the vernacular and local context. As such, these surveys should be seen as an exploratory phase that elicited information rarely collected in these settings, which is complemented by the studies presented later on.

Study participants in Yemen were older than in Ethiopia and included a small number of Somalis. Most Somalis in Yemen are refugees who have left their country due to decades of political strife. These refugees do not live in designated refugee camps, but are interspersed throughout the population and only access health services when they are referred to the hospital via non-governmental organisations that cover service costs. Most are poor, have little knowledge of Arabic and thus face difficulties to communicate with health staff. In contrast, in Ethiopia, nearly all participants were born in the country, but belonged to a large number of tribal groups, which reflects the ethnic diversity of the area and the remote location of the Southern Region, bordering Kenya and Somalia but lacking direct, paved link roads to those countries. In Ethiopia, there was a higher proportion of males than females attending the services and participating in the surveys. This is in agreement with global facility-based statistics in which most of the male-female case notification rates for TB are above 1 (Ottmani and Uplekar 2008). These gender differential rates are likely to reflect a combination of biological and socio-cultural factors which vary within local,

regional and national contexts (Diwan and Thorson 1999). It was however unusual that in Yemen the percentage of males and females was roughly equal, despite the anticipated difficulties for females to attend health services in this society. It is possible that symptomatic males experienced a similar level of difficulty to attend as females, albeit of a different nature, although previous surveys in the same setting have shown that more males than females attend the study centre. The question has to be asked whether the health workers recruiting patients were aware the researchers were exploring these issues and strove to achieve equal numbers. The issue was thus explored further in subsequent chapters with a different outcome.

The survey also included a relatively small percentage (24%) of patients residing in rural areas in Ethiopia, which has a high rural population (83%) (Anonymous 2010c), suggesting that the majority of patients selected had come from the same or other towns. The higher proportion of rural participants in Yemen compared with Ethiopia (47% in the survey compared with 76% nationally (OECD 2012)), reflects that adults are often referred, or self-refer, to the NTI, which is a national reference centre, from across the country.

Participants in both countries lived in large family units and attended the diagnostic services with several companions, particularly in Yemen – a tendency which considerably increased the cost of diagnosis in both countries, as shown in chapter 4. This finding is of particular relevance for women, who were more often accompanied than males. While females were more likely to be accompanied than men in Ethiopia; in Yemen nearly *all* women came accompanied, which perhaps replicates local socio-cultural norms, particularly among rural communities. Women in Yemen often attended with several companions (nine on one occasion). Although women in Ethiopia were often accompanied by their husbands, in Yemen nearly all women were accompanied by relatives other than their spouses. The differences between the two countries in the relationship of the companion(s) to the patient could inform health programmes whom to target for community health education.

A very high proportion of participants (especially in Yemen) had sought help in other centres before attending the study centres. Although the median number of additional healthcare providers consulted was relatively low (1 in Ethiopia and 2 in Yemen); some patients indicated they had attended many other services and others (Storla et al. 2008) have also found patients make many visits to the *same* provider. The services more commonly consulted were conventional professional medical services, which most frequently comprised private practitioners. A low number of patients indicated they had consulted traditional healers, obtained over-the-counter medicines or self-administered treatments. Repeated consultations with healthcare providers without receiving a correct diagnosis (in particular primary government health posts, private practitioners and unqualified vendors or traditional practitioners) are known to be risk factors for extensive diagnostic delay (Storla et al. 2008).

A sizeable proportion of participants in Ethiopia and Yemen had been previously treated for TB. This high proportion of retreatments could be a result of drug resistance, erroneous prescriptions, or failure to complete the treatment course (Lawn and Zumla 2011; Lonroth et al. 2010a; WHO, 2011b), although it could also reflect that since the centres are considered to be specialised TB centres by the population, a higher concentration of problematic patients attend these facilities. Encouragingly, the majority of the remaining patients had heard of TB, were aware that it could be contracted from a person with TB and that it was treatable. Conversely, a large proportion of participants were not aware of the availability of free TB treatment - a factor that adversely affects attendance at diagnostic services and subsequent registration for treatment (Long et al. 2008). Patients shared many misconceptions about methods of disease transmission. In common with patients in other settings, the most frequent misconception was transmission from 'cold air' (Sagbakken et al. 2008a). These misconceptions often have a bearing on transmission, as for example, in many countries users of public transport prefer to close the windows of the vehicle to avoid exposure to cold air, and the use of public buses has been shown to be a risk factor for transmission (Horna-Campos et al. 2007; Horna-Campos et al. 2011). As might be expected, there

was a higher level of awareness of the link between TB and HIV in Ethiopia, which has a higher incidence of HIV than Yemen.

Ethiopian and Yemeni patients' reluctance to disclose their diagnosis to anyone outside their family is symptomatic of a high degree of stigma (Baral et al. 2007; Long et al. 2001; Rubel and Garro 1992) and suggests that businesses, the civil service and key figures in the community such as religious leaders could be targeted to increase awareness and thereby reduce public fear of the disease. Although the majority of patients intended to inform others of their diagnosis, a small but sizeable percentage were not prepared to disclose the diagnosis even to family members. Family support during treatment is known to encourage treatment adherence and its absence is a known barrier to treatment completion and cure (Sagbakken et al. 2008b). Patients choosing not to disclose their diagnosis may do so because they do not have social resources, but equally cannot gain support if those around them are unaware of the cause of their illness and prescribed treatment. The adverse social consequences and stigma surrounding TB have been widely reported (Cambanis et al. 2005a; Eastwood and Hill 2004; Gebremariam et al. 2011; Liefoghe et al. 1995; Long et al. 2001). They include rejection by family and friends, divorce or reduced marriage prospects, dismissal from school or employment, social withdrawal and these consequences are particularly acute for women (Armijos et al. 2008; Atre et al. 2011; Baral et al. 2007; Gibson et al. 1998; Liefoghe et al. 1995; Somma et al. 2008).

Yemen is considered by international organisations to have one of the worst rankings of gender parity in the world, ranking 83<sup>rd</sup> out of 86 non-Organisation for Economic Co-operation and Development (OECD) countries (OECD 2012) and women living in the predominantly tribal cultures in the north of the country are considered to have fewer freedoms than their southern counterparts (Date and Okita 2005). A majority of Yemeni respondents acknowledged the difficulties women faced to access healthcare. The low number of Ethiopian respondents believing women faced difficulties may reflect greater civil liberties; however since Ethiopia only ranks 64<sup>th</sup> in the 2012 Social

Institution and Gender Index (SIGI), OECD, the low response rate may understate the extent of the problem and these data need to be interpreted with caution and are further explored in chapter 7.

Patients in Ethiopia and Yemen interviewed the second day showed similar patterns of understanding and misunderstanding about their diagnosis, with a significant number of patients diagnosed as having TB by the doctors indicating they did not have TB, and conversely, patients with other diagnoses recorded in their records indicating they had understood they had TB. The survey cannot differentiate legitimate answers from those of patients denying their diagnosis for fear of stigma, or indicating they had TB in the hope of obtaining financial support from the centre, nevertheless, high numbers of patients in Ethiopia complained that they did not have much opportunity to ask questions of the doctor, with nearly half reporting they were unaware of their diagnosis. Although the majority of patients in Yemen expressed they did have an opportunity to ask questions and only a small minority reported they were unaware of their diagnosis, when the concordance between the patients' and doctors' reported diagnosis is examined, there was less agreement in Yemen - perhaps a reflection of a reduced willingness to voice criticism among Yemeni patients, as discussed below. On balance, these findings suggest that there is considerable room for improvement in the way the diagnosis is communicated to the patient by health professionals and a need for regular awareness-raising in the community.

The high level of general satisfaction expressed by patients completing the diagnostic process concerning their experience of diagnostic services, their organisation and management, staff attitude and information giving should be interpreted with caution, since satisfaction surveys tend to elicit uncritical and non-confrontational responses, especially if these are conducted in the same setting where the service is provided. Moreover, disadvantaged populations may not have experienced a high standard of service that could serve as a benchmark for comparison. The subsequent responses of patients in Ethiopia concerning lack of opportunity to ask questions to the medical staff and lack of understanding of the disease they had been diagnosed could be considered

suggestive of this limitation, since they convey dissatisfaction. The lack of criticism of diagnostic services from Yemeni patients might also reflect genuine satisfaction and perhaps an improved patient experience as a result of the study effect, or the same reluctance to criticise. These issues are more readily explored with other research approaches and these responses need to be contrasted with the findings reported in chapters 6 and 7, where patients' views were explored in more detail and using different research methods.

Patients in Yemen indicated they were in receipt of substantially more material support, or assistance in kind, than Ethiopian patients. In the analysis of the patient costs associated with diagnosis in chapter 4, the median cost of attending the clinic for 2 days was highest in Yemen and lowest in Ethiopia and Yemeni patients might therefore have needed a higher level of support. The difference in the relationship of the main person supporting the patient in both countries is likely to reflect cultural differences in social and family structures and provides useful contextual information for community and facility-based health programmes. These issues are therefore explored and discussed extensively in Chapters 6 and 7.

## **Conclusion**

The surveys presented in this chapter therefore established that a range of factors were at play to either protect or hinder patients' attendance at diagnostic services in Ethiopia and Yemen.

Protective and inhibiting factors do not of course operate in isolation but are interrelated and often combine to have multiple effects on the patient. Many of the factors identified were common to patients in both countries, while others were quite distinct.

In both countries, and particularly in Yemen, patients attended with several companions, and more women were accompanied, almost without exception in Yemen. Female patients in Yemen were considered by research participants to face many difficulties in accessing healthcare, including first needing to ask their husband for permission to attend and to care for other relatives, being unable to travel alone to health services and not having access to household funds; while in Ethiopia, few

participants cited difficulties for women. In Ethiopia, patients were accompanied by their spouses, while in Yemen patients were accompanied by other relatives. Yemeni patients received more financial and material support, in addition to the high degree of companionship already mentioned, which again came from relatives other than spouses.

The majority of patients had heard of TB, knew it was infectious and treatable, but importantly were unaware of the availability of free treatment and had many misconceptions about the methods of disease transmission, which could have adverse consequences for treatment access and for the spread of the disease. Similarly, a sizeable number of patients were unclear of their diagnosis, pointing to the need for improved doctor-patient communication. The surveys conveyed that a high degree of perceived or actual stigma prevails in Yemen and Ethiopia, since the majority of participants intended to disclose their diagnosis to family members alone and some to nobody at all. The difficulty in informing others increases the likelihood of social isolation and default from diagnosis or eventual treatment. Yemeni patients had consulted more healthcare providers prior to attendance at the Centres than Ethiopian patients; nevertheless participants' health seeking behaviour in both countries mirrored that of patients in other settings.

## Chapter 6

### Exploring barriers and enablers to accessing TB diagnosis and treatment in

#### Sana'a, Yemen

*"Stories have to be told or they die, and when they die, we can't remember who we are or why we're here."*

— Sue Monk Kidd, *The Secret Life of Bees*

*"A story has no beginning or end: arbitrarily one chooses that moment of experience from which to look back or from which to look ahead."*

— Graham Greene, *The End of the Affair*

#### Introduction

Barriers and enablers to complete the TB diagnostic process are likely to range from setting-specific to generic factors applicable to most contexts. Factors affecting the ability of adults to attend diagnostic services, complete the diagnostic process and register for treatment have not been studied in Yemen; therefore there is scanty information to indicate which barriers and enablers might be operating in this society.

This is thus the first attempt in the country to use qualitative methods to explore the views of adults attending diagnostic services and indeed one of the first studies to employ qualitative research methods to elicit patients' perspectives in the area of TB or health in general.

The chapter aims to describe the barriers and enablers for the completion of diagnosis and registration for treatment as experienced by IDI and FGD participants in Sana'a, the capital of Yemen. The chapter also includes patients' suggestions for improving health services to facilitate diagnostic completion. In addition, the chapter explores questions raised in the quantitative chapter, namely explanations for the disproportionately high expenditure of patients from rural areas or towns outside Sana'a, and the detail of the unspecified costs that comprised a large proportion of expenditure for a minority (12%) of patients.

Yemen is a traditional Muslim society with a majority Sunni and Arab population. As such, barriers and enablers operating in this setting were considered likely to differ in many respects from those in Ethiopia, described in chapter 7, and are thus described separately. A discussion of the commonalities and differences in findings between the two study sites takes place in the discussion chapter. The views of participants were elicited through IDIs and FGDs with selected patients who had completed the diagnostic process, patients who had registered for treatment and IDIs with individuals not completing the diagnostic process.

### **Methodology**

The methodological framework and methodologies employed for the different study components common to all countries are laid out in the general methodology chapter. Additional methods specific to the qualitative study in Yemen are described here, including adaptations that were made to the study organisation to suit the study site and country context.

Information was elicited using IDIs and FGDs with adults > 18 years old who had attended the NTI in Sana'a during the study period (February 2009 to December 2010). The NTI is a large TB referral centre that provides clinical diagnostic services to referred and self-referred patients. Diagnostic services include low cost medical consultation, sputum smear microscopy, X-rays and culture facilities. The latter is conducted for patients failing to respond to first line TB drugs and needs to be specifically requested by medical staff. Patients attending the centre were screened using the SSM and SMS schemes, which were alternated on a monthly basis for the duration of the study.

#### *Selection of research participants*

Potential participants for interview were selected from a logbook of TB suspects, kept by the country research team as part of the research monitoring process. Patients were placed into 4 categories: those that had completed the diagnostic process; those that had failed to return in the succeeding days and thus had dropped out of the process; and smear positive patients that had gone on to register or who had failed to register for treatment. If a patient did not complete smear microscopy, the social worker followed up with a call after 3 working days. The social worker called the patient

twice before categorising them as a defaulter from diagnosis. The intention was to categorise patients as having completed diagnosis after discussing smear microscopy results with a physician. In practice, however, the research team found that it was difficult to secure an interview as patients were inclined to rush off; therefore several patients were interviewed while waiting for test results and/or the final consultation with a clinician. Patients that had taken part in first or second day quantitative interviews were not included in the qualitative study to avoid overburdening them. Participants were selected with a view to obtaining a broad demographic and socio-cultural profile, following the sampling frame described in the methodology chapter (section entitled 'Study participants and approach'). Particular emphasis was placed on securing the views of patients from rural and urban locations in different geographical areas. Rural residency had been found to be a key factor associated with higher patient expenditure earlier in the study and has been found to impede patient attendance at diagnostic services in other contexts (Cambanis et al. 2005a; Cambanis et al. 2007; Storla et al. 2008; WHO 2005). Attention was also paid to the selection of immigrants, since mobile populations such as immigrants and migrants are known from international literature to belong to the marginalised populations that are particularly vulnerable both to contracting the disease and to experiencing difficulties in accessing diagnostic and treatment services (Gilpin et al. 2011; Lienhardt et al. 2012; Long et al. 2008; Lönnroth et al. 2010b). Somali immigrants to Yemen are known to be a vulnerable group.

#### *Recruitment of participants*

Patients who had completed or abandoned the diagnostic process, and registered or not registered for treatment, were contacted by research staff by telephone or home visit, or approached in person on attendance at the TB Centre, and invited to attend an individual interview or participate in an FGD. An interview appointment was made with those that consented. Some IDI participants went on to take part in an FGD. Participants continued to be recruited to each interview category until a variety of patients with differing profiles had been interviewed and much of the material given by

patients was familiar to the research group, known in the literature as saturation point (Strauss and Corbin 1990).

### *Staffing*

Three social scientists (one male and two female) were employed to conduct IDIs. The male was a university lecturer in the School of Sociology and the two females were students in social work. All had received training in qualitative research methods and had experience of conducting individual and group interviews. They were closely supervised by the local project co-ordinators, who had completed training in qualitative research methods at LSTM. The co-ordinators managed the qualitative component of the study, as well as contributing to the conduct of IDIs and leading the FGDs.

### *Organisation of interviews and FGDs*

In general, interviews with women were conducted by the two female social workers (one leading and the other making additions and seeking clarification) and interviews with men by the male social worker. Gaining access to research participants' households often required all three interviewers to be present. This gave the researchers the flexibility to cater for the presence of a male or female member of the household (in addition to the patient) and conformed to religious and cultural norms requiring females to travel with a male companion (OECD 2012).

Yemeni society is structured hierarchically along tribal, ethnic and gender lines, more commonly in the more conservative north (McLaughlin 2007). Females may not feel able to talk frankly in front of males, or younger people in front of older people. For this reason, FGDs were held separately for males and females and further divided into old (aged 40 years or more) and young patients.

Patients' expenses for subsistence and transportation to attend an FGD away from home were paid, and financial incentives were given to the poorest patients at the discretion of the social worker, based on an informal observation of the patient's economic situation.

All FGDs and the vast majority of IDIs were recorded on a digital recorder, but a minority of participants did not consent to an audio recording and interviewers took handwritten notes.

#### *Location*

The majority of women's IDIs were held at the patient's home, or at a health clinic if held in the afternoon. The research team sent social workers in a car to bring patients to the clinic. Men's IDIs were held in a variety of locations including the study car, restaurants or cafés, the patient's workplace or at home and, in one case, over the telephone. Focus Group Discussions were held in the TB Centre or a health clinic.

The clinic is seen as an acceptable public venue for women to attend alone. Upon seeing two female social workers in the car, some families allowed female patients to attend IDI or FGD without male company. Women often brought their children.

#### *Transcription and translation*

A professional translator and native Arabic speaker was employed to translate and transcribe FGDs and IDIs to English. The translator was of part Yemeni heritage and was familiar with the Arabic spoken in Yemen. Translations were checked for accuracy by randomly selecting translated transcripts and comparison with the original interviews by the local coordinators. Discrepancies were discussed with the translator, the PhD research student and the field research team.

#### *Data analysis*

The same analytic approach was taken as for Ethiopia, as outlined in the methodology chapter.

#### *Number of IDIs and FGDs conducted*

In-depth interviews and FGDs were conducted with patients who completed the diagnostic process (16; 2), abandoned diagnosis (11; 0) and registered for treatment (20; 10). There were few smear positive patients that did not register for treatment and these had died or moved out of the area,

therefore no interviews were held in this category and the research group was unable to identify sufficient participants not completing the diagnostic process to conduct FGDs.

### *Presentation of findings*

Data are presented using the same approach as in Ethiopia, as described in the methodology section, chapter 4. As might be expected, participants in IDIs and FGDs who had registered for treatment had similar views to those that completed diagnosis regarding their experience of diagnostic services and facilitators and inhibitors to attendance and completion. Their views on the diagnostic experience are thus presented jointly; while their account of barriers and enablers for treatment services, which are distinct, are reported separately. The FGDs with patients completing diagnosis elicited new information to that from IDIs with the same group, principally with respect to the differential needs and experiences of men and women in accessing healthcare, the impact of disease status on social and work relationships and public awareness of TB. Where the discussions did not provide fresh perspectives, but merely supported existing findings, participants' views are not reported.

## **Results**

### **Characteristics of participants**

Participants included 16 adults who had completed and 11 who had abandoned the diagnostic process. Participants completing diagnosis had ages ranging from 22 to 60 years; six were female and 10 male. One participant was a widow, two single and 13 married. The majority had children. Four participants had attended school and 12 had no schooling. Among male participants, one was a student, five were working, two were retired, one unemployed and one was unable to work. Among females, two generated an income working from home as a tailor/seamstress and one looking after livestock. Nine patients resided in Sana'a and seven in other towns, as shown in table 6.1. Seven were screened using the spot-spot-morning and nine the spot-morning-spot schemes.

The eleven participants abandoning the diagnosis were between 20 and 83 years old, three were female and eight male. Six were married, 3 single and the marital status of two was unstated. Eight participants had/were attending school, one had no schooling and the educational status of two was unstated. One female was a student, one was not working and the work status of one was unspecified. Five of eight male patients were working, one was retired, one a student and one was not working. Ten patients resided in Sana'a and one in Dhamar (110 km). Four patients were screened using spot-spot-morning and 7 spot-morning-spot. A summary of their characteristics is included in table 6.2.

Participants in the IDIs with patients that had registered for treatment comprised 7 male and 14 female. Most of them were adults up to 50 years old (table 6.3). However, later it was recorded that the age of one participant was 13 years. The FGDs were held with male and female patients (table 6.5).

Participants in the FGDs with patients completing diagnosis included one group of males and one of females from both urban and rural areas. There was one Somali participant in each of the two FGDs. A summary of their characteristics is included in table 6.4.

**Table 6.1. Characteristics of IDI participants completing the diagnostic process**

Track no.	Sex (M/F)	Age (years)	Married (Yes/No)	Children (Y/N; Number)	Education	Working	Ethnicity	Address (travel time from Sana'a)	Rural or Urban	SM Scheme
1	F	54	Yes	Yes	No schooling	Looks after livestock		Al-Haima, west of Sana'a		SSM
2	F	37	Yes	Not known	No schooling	No. Housewife, Tailor		Al-Hada area (Shamar) (2 hrs 30 mins)	Rural	SSM
3	F	≥50	Widow	Yes (7)	No schooling	No		Sana'a		SSM
4	F	25	Yes	Yes	No schooling; illiterate	No		Mareb (2 hrs 15 mins)	Rural	SMS
5	F	40	Yes	Yes (10)	No schooling	No		Harad (5 hour)		SMS
6	F	49	Yes	Yes (6)	No schooling	No. Seamstress, works from home.		Alsafia, Sana'a		SMS
7	M	25	No	N/a	No schooling	No	Somali	Sana'a		SSM
8	M	Old	Yes	Not known	No schooling	Working		Sana'a		SSM
9	M	Young	No	N/a	Level 7 schooling; literate	Unable to work		Aldairi zone, Sana'a		SMS
10	M	55	Yes, 2 wives	Yes (6)	No schooling	Retired, but still working.	Murad tribe	Sana'a		SSM
11	M	25	Yes	Yes	Yes	Selling vegetables		Nogrom/Nokom, Sana'a		SSM
12	M	60	Yes	Yes	No schooling	Farmer		Nehm (tribal area between Sana'a and Mareb)		SMS
13	M	50	Yes	Yes (11)	No schooling	Retired soldier		Yareem (Yemen Highlands, south-west)	Rural	SMS
14	M	25	Yes	No	Yes	Yes. Electrical engineer		Rada'a, south of Sana'a, 180 k (2 hours)	Rural	SMS
15	M	42	Yes	Yes	No schooling	Yes. Painter/decorator		Shmila, Sana'a		SMS
16	M	22	Yes	No	In education, level 2	Student at university; Quran teacher.		Sana'a		SMS

**Table 6.2. Characteristics of IDI participants abandoning the diagnostic process**

<b>No.</b>	<b>Sex (M/F)</b>	<b>Age (years)</b>	<b>Married (Yes/No)</b>	<b>Education</b>	<b>Working</b>	<b>Address</b>	<b>Rural or Urban</b>	<b>SM Scheme</b>
<b>1</b>	F			Not known	Not known	Birr Obid, Sana'a	Urban	SSM
<b>2</b>	F	20s	No	Undergraduate student	No. Student	Sana'a	Urban	SMS
<b>3</b>	F	Young	Yes	No	No	Sana'a	Urban	SMS
<b>4</b>	M	Young	Yes	Yes	Yes	Musaik district, Sana'a		SMS
<b>5</b>	M	Young	No	Yes	Yes, at army maintenance base	Sana'a	Urban	SSM
<b>6</b>	M		Yes	Yes	Yes/student	Sana'a	Urban	SMS
<b>7</b>	M	Young	Yes	Yes	Yes	Sana'a	Urban	SMS
<b>8</b>	M	Young	Yes	Yes	Yes	Hada, Sana'a	Urban	SMS
<b>9</b>	M	Young	Yes	University degree, Computer sciences	Yes	Sana'a	Urban	SSM
<b>10</b>	M	Young	No	Yes	No	Madbah, outskirts Sana'a	Urban	SSM
<b>11</b>	M	83		Not known	No, retired	Thamar (100 km)	Urban	SMS

**Table 6.3. Characteristics of IDI participants registering for treatment**

<b>No.</b>	<b>Sex (M/F)</b>	<b>Age (years)</b>
1	M	23
2	M	29
3	M	38
4	F	20
5	M	23
6	M	35
7	M	24
8	F	13
9	F	27
10	F	22
11	F	22
12	F	45
13	F	40
14	F	50
15	F	16
16	F	24
17	M	20s
18	F	21
19	F	24
20	F	20
21	F	26

**Table 6.4. Characteristics of FGD participants completing the diagnostic process**

<b>No.</b>	<b>Sex (M/F)</b>	<b>Ethnicity</b>	<b>Address</b>	<b>Rural or Urban</b>
<b>1</b>	M	Somali	Taiz	Urban
	M		Madbah	Urban
	M			
	M		Al-Hada	Rural
			Maeen Mathbah, Sana'a Ein, Sana'a	Urban  Urban
<b>2</b>	F	Somali		
	F			
	F			
	F			
	F			

**Table 6.5. Characteristics of FGD participants registering for treatment**

<b>No.</b>	<b>Sex (M/F)</b>
<b>1</b>	
<b>2</b>	F
<b>3</b>	M
<b>4</b>	F
<b>5</b>	
<b>6</b>	M
<b>7</b>	
<b>8</b>	F
<b>9</b>	F
<b>10</b>	M

## Experiences and perceptions of diagnostic services

### *Positive perspectives*

Positive viewpoints put forward by patients completing the diagnostic process included a smooth and quick diagnostic process that was easy to complete and did not pose difficulties<sup>Q1-2</sup>. The service was seen to be well organised considering the volume of patients and accommodating of late-arrivals; medical care satisfactory and hygiene adequate.

Similarly, some patients not completing the diagnostic process found the TB Centre well equipped, modern and efficient<sup>Q4</sup> and doctors were perceived to be modest<sup>Q4</sup>. Some appreciated that the Centre specialised in TB<sup>Q3,4</sup>, was able to diagnose their condition<sup>Q3,4</sup> and allocated a doctor to every patient.

Examples of positive diagnostic services perspectives:

Q1 *“Everything is easy and quick and cheap [...]”* The services were *“Good. Nothing really [bothered me]. It was quick and easy first day and second day.”* (Older, male patient, completed diagnosis, IDI)

Q2 *“It was good. We paid for the admission ticket, had the x ray done, paid 200 rials and were asked to the another phlegm test and to come back next day. We spoke to the doctor and were told she is having infections. We explained to him that she is having breathing difficulties at night and cough. She would not move from the pain. He gave us the medication and told us she will be fine.”* (Family of young, female patient, completed diagnosis, IDI)

Q3 *“[...] in the TB hospital (sic)? It was positive. I wish if I was treated there from the first place. [...] Because they are specialists. But when I was in the [public] Hospital I stayed and waited there for eleven days. They only found out it was TB just in the last day! The doctors were not sure if it was TB or not. One would say ‘It’s TB’, the other says ‘No it’s not’. Then Dr. [...] looked at the X-ray and the tests, and then said ‘It’s the symptoms of TB’. Then he instructed to give me the appropriate treatment [in the TB Centre].”* (Young, male patient, did not complete diagnosis, IDI)

Q4 *“The services here are much better than the [private] hospital and preferable. [...] Because the [private] hospital diagnosed me with infection. I paid over YER 5,000. I had been using the medication from the [private] hospital for a month, but [it] did not help at all! [...] Here is better. Doctors are humble. But there you need to wait over an hour to be seen by a doctor.”* (Male patient, did not complete diagnosis, IDI)

### *Negative perspectives of diagnostic services*

Patients completing diagnosis also voiced strong criticism of the failure to prioritise or give extra attention to very sick or elderly patients<sup>Q5,8</sup>, inadequate waiting areas<sup>Q8,11</sup>, long waiting times for smear test results and unprofessional staff behaviour. The latter included preference for patients with personal connections (at X-ray) and requesting additional payments. Concerns were expressed about the shortage of doctors<sup>Q7</sup>, the lack of hygiene and of measures to prevent cross infection<sup>Q8</sup>. Individuals voiced discontent and surprise at having to pay for treatment if they had a diagnosis other than TB<sup>Q5</sup>, at being referred for blood tests outside the Centre and disappointment at not receiving free food parcels. Minor criticism came from a patient delayed due to an electricity failure in the Centre. The son of an older, female patient with a 5 day diagnostic process was highly critical of the service<sup>Q11</sup>, although the patient was reluctant to complain. They had arrived on a Tuesday but the clinic was closed from Wednesday to Friday for International TB Day and the weekend. On Saturday, there was no electricity and the patient had to return on Sunday to submit sputum. He was unhappy with the cost and organisation of services, lack of information, perceived corruption and the facilities at the Centre.

Patients that did not complete diagnosis had similar criticisms of the poor hygiene and risk of cross-infection<sup>Q12,13</sup>, requests for payments without receipt and overcharging. Patients were critical of the limited facilities, old buildings and unpleasant physical environment<sup>Q10,13</sup> and were concerned that the consultation room was crowded<sup>Q13</sup> and that patient numbers were too high for laboratory staff<sup>Q9,12</sup>. A female patient found the Centre disorganised and confusing and was unclear where to go, feeling everyone was rushing her. She was uncomfortable at being seen by a male X-ray operator and indicated these facilities should be segregated by gender.

Negative perspectives of diagnostic services:

Q5 *"Some patients come in a coma, but they are still asked to come back in 2 months' time! [...] I was shocked when they asked me to pay for the medication. I thought its [it was] state funded. I had to borrow some money [...]. Financially, I was told you get a card with which you [get] free medication paid by the government."* (Older, male patient, completed diagnosis, IDI)

Q6 *"[...] the only problem is the hygiene level is not up to standard, and visitors and patients should be given masks for their safety and for those who accompany the patients. [...] Patients and their companions must be given masks on arrival. Even if that was for a cost, and as you know TB is an infectious disease. You must know better than me - you are a doctor. Even if you want to charge for these masks, that is fine; 20-50 rials that is fine. I mentioned that to the doctor."* (Husband of young, female patient, completed diagnosis, IDI)

Q7 *"There is a shortage in the doctors in this centre. I have seen some patients suffering in [on] the ground and there's no doctor to see them. Some get upset and leave the centre without being seen by doctors!"* (Son of older, male patient, completed diagnosis, IDI)

Q8 *"If you could have better patient waiting areas that would good, because I noticed some old patients come from long distances and they join the queue with the others. That must be very difficult to the [for them]. [...] Everything is fine in the centre, but as I said you need to have a better waiting area, because I saw patients on the floor everywhere and some others in their cars."* (Son of older, female patient, completed diagnosis, IDI)

Q9 *"[...] when I come in at the Centre's door, I do not feel that I am in a hospital; I feel like being in a market. I don't feel that I am in a hospital - a respected hospital which should be having its glory! [...] The rooms, the people there... management wise there is no order. [...] you do not feel that you are in a hospital which [is] supposed to be fighting a very dangerous disease. Maybe the clinics locations and labs are not in the right place! You feel as if you are in a market and going from one shop to another; crowds in all over the place (sic). Then the hospital loses its respect and status. [...]"* (Young, male patient, did not complete the diagnostic process, IDI)

Q10 *"To be honest the centre is better than the [private] hospital, but the buildings are old. You need more chairs and clean facilities and sitting area."* (Male patient, did not complete diagnosis, IDI)

Q11 *"There is no single note to say what the [clinic] opening hours are. People start gathering outside since 6:30 a.m. and the doctor comes at 8:30. When you get in it's already 9:00. We came on Tuesday for the phlegm test. We gave the specimen on Tuesday and were asked to come on Wednesday for the result. On Wednesday they had a celebration, a big crowd was outside, but there was no doctor and people came from a very far distances such as Alhada, Bareeda, Emrand and from far places. After all this you find there is no doctor! Why did these people came - is it to do nothing? [...] At least make a note [of the holiday for International TB Day] or tell the others that Wednesday is a day off. [...] Because some patients had to come from a very long distances (sic) and spent a lot of money, but being turned back as easy (sic) as that and we heard this is a good centre under the Japanese supervision, but the doctors are not helping! [...] There is even no seats to sit on it (sic [in the waiting area]). Patients are sitting on the floor. There are four or five chairs and the patients are over 250. (Son of older, female patient, completed diagnosis, IDI)*

Q12 *"I didn't know where the doctor was, or where to go, or how to register yourself. I had no idea at all. [...] [Without the family friend who works in the TB Centre assisting me] I would be in a state of emergency, because I did not know what to do, or where to go and too many patients were around and you feel it was unorganised. You go there and the doctor is in one place and the clerk in another place. You feel lost. It is not well organised. [...] The saliva test was always late and sometimes when I had to write down my details they would hasten me. They would not let me do it properly. When I was with the person who helped me I was fine and completed my details, but the others would hasten me. Everything has to be quick that's all. And in the laboratory there were two female staffs and one male staff, that's all. [...] And the patients are too many. We can't finish it early with this huge number of patients! And the laboratory was not clean and everyone was allowed to walk in, and the stuffs [equipment] were not very hygienic, and things are mixed up [...]. And the X-ray room for the chest test, there should be two rooms; one for the females and one for the males. The staff who did the X-ray for me was a male and I was very embarrassed to be honest. If it was a female staff it would have been better. And even when we had to change our clothing, it had to be very fast and we were really embarrassed. And because I was really ill I didn't bother and I was concerned about my case."* (Young, female, did not complete diagnosis, IDI)

Q13 *"Regarding the negatives, I have done the two tests the phlegm's and x ray. My lung was found clear, but when was waiting for the X-ray to come out it takes 30 minutes and then they come out in groups [of] five to ten and the patients just run in to the doctor's room without queuing up and the doctor was not happy with what was happening. My main concern is if anyone of those patients was having a contagious illness, that is enough to pass it to all of us! [...] Unfortunately, we live in a backward society and they lack awareness! They are always in hurry and only care how to be first to be seen!*

*[...] To be honest, the general public's behaviour is more daft than the doctors'. The staff and doctors' attitude was good, but what annoys me is the attitude of the patients. For example the lab door is open all the time and the patients walk in freely. This is not very healthy. There are specimens in the lab and these patients are having contagious disease. [...] They should be seen through the window. To be honest there's a kind of negligence. One more thing... the doctor's room is open and patients just walk in big numbers, as if it's a court and every patient comes in and put his file on the top! There should be a secretary. If the patient wants to ask the doctor something in private, there's no chance. It is just a mess and the administration should do something.*

*[...] the smell of the centre is a bit strong. The main thing to any patient that his wellbeing should be taken in to account. Unfortunately the surrounding atmosphere is not helping the patients of chest disease. There is not even one single tree in the centre. As you know patients with chest diseases need a clean air more than anyone else. [...] What made things worse is, the roads leading to the centre are unpaved. If someone walks, the dust goes everywhere and makes things worse! [...] [Regarding the waiting area], I waited in my car for 45 minutes. If I had not come in my car, it would have been very annoying. As I said earlier, there's no good scenes. No trees. No green spaces. Unfortunately, there was no canteen at the centre and that makes things difficult for the patients."* (Young, male patient, did not complete diagnosis, IDI)

### **Length of the diagnostic process**

Diagnosis for most patients took two working days to complete, or less if the patient was given a first-day diagnosis, and two patients required 3 and 5 days. Among the latter, one sent for extra money from his village and the delay for the other was due to a combination of misinformation and operational delays. Patients reporting prolonged waiting times indicated these were due to blood tests in external laboratories, the late release of smear tests and long X-ray waiting times. Some patients found the diagnostic duration reasonable or quick and two patients remarked that attendees needed to be patient and accept the time required to process samples. There was recognition that staff attended to patients as quickly as possible given the high number. The family attending for 5 days was extremely dissatisfied with the slow service, as stated above. A few patients suggested that a same-day diagnosis would assist patients to complete diagnosis.

The majority of patients not completing diagnosis had not returned on the second day, although some had returned at a later date. Several patients remarked that the first day was quick; lasting only 2 hours in one case. A female patient was pleasantly surprised at the speed of the service and said: *"I didn't expect it to be that quick. We walked in, had the test done and went back home"* (IDI). Others were dissatisfied, including a young male who was frustrated by delays in the centre. He had undergone tests over an eleven-day period in a public hospital before referral and did not understand the need for further tests or submission of multiple sputum samples.

### *Waiting time for registration and initial consultation*

The waiting time for an initial consultation for patients completing diagnosis ranged from being seen immediately to 1.5 hours. Several patients found this time short or acceptable, one that it was long and one recommended reducing it. Patients arriving early were more likely to avoid the queues, obtain a registration card and to be seen promptly. Many patients seemed aware of this; however one patient described waiting outside the building from 6.30 a.m. and not being let in until 9.00 a.m. A patient complained there was only one doctor on duty which caused delay.

Patients not completing diagnosis reported shorter waiting times to see a doctor (from no wait to 15 minutes). One female had a family friend working in the Centre, who helped her avoid waiting for the clinic. Another patient arrived early and observed that patients arriving between 10.00 and midday waited for longer.

#### *Waiting time for tests*

Smears and X-ray results in the Centre are released collectively at two points in the day. Patients completing diagnosis reported waiting between 1 hour 15 minutes and 2 hours for test results. Some patients found this wait reasonable or quick and one complained it was lengthy. Patients not completing diagnosis reported tests were undertaken immediately: *“The phlegm [staff] were nice with us. As soon as we entered they did the tests [...].”* (Young male patient, IDI). Patients waited between 15 minutes and 2 hours for test results. Some found the wait quick or acceptable: *“It was so quick. It only took 15 minutes and that’s a fair time”.* (Female patient, IDI). Others found 30 minutes a long time to wait and some patients attributed the long wait to the high workload and understaffing in the laboratory. The grandchild of one patient reported that a 2-hour wait for test results was a bit lengthy compared to a 30 minute wait in a private hospital.

#### *Opening times*

The Centre opens to the public from 8.00 to 13.00, Saturday to Wednesday, and half day Thursday. Many patients completing diagnosis indicated the hours were reasonable and standard for services. Some considered that it was important for doctors to rest to work well. One patient observed that doctors arrived late and the Centre closed earlier than other services, which closed at 14.00. He suggested extending opening hours and introducing a second work shift to help patients living far away to return home the same day.

Two patients not completing diagnosis suggested extending the opening times to help patients reach the Centre: *“[...] maybe if they open to late afternoon that would help, especially for those who come from far places”* (grandchild of older, male patient, IDI). *“I feel sorry for them [patients*

*that have to return], because the Centre is outside Sana'a in a remote area"* (Young, female patient, IDI).

### **Interaction with staff**

The majority of patients completing diagnosis and their companions commented the staff were courteous, helpful and had a positive attitude. Some felt doctors listened carefully. Several patients however were critical of staff issuing favours and committing financial improprieties. A male patient cited staff selling medication on the black market<sup>Q1</sup>.

Example of negative views of staff:

(Patient completing diagnosis, IDI)

Q1 *"[...] Change the style of administration and the way they give the medicines, better than selling it in the black market. [...] I have heard from outside the hospital that they sell the medicine in the market."* (Male patient)

Patients not completing diagnosis were largely complimentary about the Centre's staff, describing them as respectful, helpful and cooperative<sup>Q2</sup>. Some commented doctors listened carefully<sup>Q3</sup>.

Examples of positive views of staff:

(Patients not completing diagnosis, IDI)

Q2 *"I was dying. I was very ill, then I started taking the medication which really helped me and I became [healthy] like before."* (Male patient, receiving TB treatment).

Q3 *"I walked in, explained to him about my case, he listened carefully, then sent me to make the tests. You feel that they are listening and care about you, not just sending you to the check up without listening to you."* (Young, female patient).

In contrast, a young male felt the doctors were only interested in whether or not he had TB, rather than investigating other diseases, as they did not request blood tests, as previous doctors had done. He expressed that staff should close the door of the laboratory and consultation rooms to stop patients walking in and out and spreading infection. The grandchild of an elderly male patient reported rude treatment by laboratory staff.

### **Access to information**

A few patients completing diagnosis felt they had received adequate information. One felt the doctor's advice was appropriate and the diagnosis convincing, and two found they were able to ask all they wanted. The majority of patients, however, did not ask the questions they would have liked about their health, procedures, treatment or administrative matters. Reasons for being unable to ask included the short consultation time, busy and crowded consultation rooms, arriving late and not wanting to delay the doctor, not expecting the doctor to answer and having a preconceived idea of the cause of the illness. Some patients finished the process without understanding whether or not they had TB. A few reported the doctor said they were "suffering from *infections*", but were unclear what this meant and would have liked to ask more about their disease. Others did not ask or receive information about TB during their visit. A patient wanted to ask the causes of lung and bone TB. Another TB-positive male had many questions such as recommended diet, the consequences of delaying treatment or missing doses, whether his wife (who had TB) should return for retesting and whether TB affected female fertility. The son of one patient voiced dissatisfaction about a lack of information in the Centre concerning opening hours, holiday closure and the need to fast before submitting sputum samples (which is not a requirement). He did not ask questions as consultation time was short and wondered why patients had to attend the Centre for 3 days to take treatment instead of being referred to the DOTS centre. One patient did not understand why medication was not free. Another commented doctors did not give information to patients that looked in poor shape.

A few patients however were waiting for the final consultation at the time of interview and may have had a further opportunity to ask questions. They wanted information about their diagnosis, whether they had TB, whether it was infectious and its duration, treatment and preventive measures to avoid deterioration. One patient and her brother were informed on the first day that she had fever and chest infection and was given medicine. They did not ask questions since: "*It [the initial consultation] goes very quick[ly]. [The] doctor sees them [the patients] one after another*".

A minority of patients not completing diagnosis was able to ask information from the doctor, concerning for example symptoms of haemoptysis and tiredness and the risk of infection after treatment initiation and were satisfied with the response. A few reported receiving verbal or written information about TB; including those not having TB. A male patient read the information displayed on the posters and brochures; another was given an information booklet: *“From a booklet. The doctor gave it to me. [...] They told me that it [the disease] causes blood loss from the mouth, fever, cold, weakness and weight loss”* (IDI).

Like those completing, the majority of patients in this group felt unable to ask questions. Some cited tiredness and not being present at the consultation and the crowded consultation rooms, which created a lack of privacy and embarrassment: *“If the patient wants to ask the doctor something in private there’s no chance. It is just a mess and the administration should do something. [...] In the TB centre [...] everything is in a hurry”* (Young, male patient, did not complete diagnosis, IDI).

### **Cost of attending diagnostic services**

The economic situation of patients completing diagnosis included patients with *no or irregular household income* – the unemployed, patients working without contracts, in subsistence farming, food/livestock sales and piece work – and patients with *regular income* and secure employment. Those with *no or irregular household income* or employment had fewer financial reserves and were less likely to be skilled and educated than those with a *regular income*.

Among those without financial reserves was a female patient with 6 children, 2 dependent grandchildren and an unemployed husband. The patient sometimes worked sewing to support the family and her 16 year old son occasionally sold Qat. This income was *“barely enough to survive our day”*. A male patient had an *irregular income* delivering vegetables; while a male university graduate had a *regular income* working as an electrical engineer.

Patients not completing diagnosis did not appear to be worse off than their counterparts. The economic situation of one patient was particularly difficult, as he had regular employment in the army but his low income (YER 20 - 30,000/£60 – 90.00 per year) was used to support his parents and seven brothers. Another undergraduate student had been in financial hardship since her father had lost his job: *“He is unemployed [...]. He worked as an accountant, but now he has been suspended.”* (Young, female IDI). She had been working as a teacher for deaf children to finance her degree but had left her job after 2 years without pay and she believed the dusty conditions in the mountains where the school was located had provoked her illness. Other patients were more affluent, affording hotel accommodation and diagnostic service charges, and included a computer sciences graduate who had held several jobs including in a national newspaper.

#### *Direct patient costs and affordability*

Patient costs included transport costs, subsistence, accommodation, clinic fees and medication and private tests requested by the Centre. Transport costs comprised the return journey to the clinic and the commute between the clinic and the city centre for eventual additional tests.

Patients completing diagnosis reported spending between YER 7,000-8,000 (£21-£24) on the return fare to the clinic and between YER 300 and 400 (£0.90-£1.20) on the commute between the clinic and the city centre. Reported expenditure on subsistence was YER 7,000 / day (£21.00) and YER 2,000 / day (£6.00) on food. Clinic fees ranged from YER 300 to 650 (£0.90-£1.90), private tests from YER 150 to 3,000 (£0.45-£8.90) and non TB medication, YER 5,000 (£15.00). A few patients described clinic fees above the standard charge; reporting YER 250-300 ( £0.74 - £0.90) for sputum tests or X-rays, as opposed to the standard YER 200 (£0.60). For one patient, the total cost was higher as the process lasted 5 days, inflating subsistence costs. Transport and subsistence costs often increased with accompanying persons. For example, an older female travelled by minibus for two and a half hours with her brothers and mother from rural Alhada at a cost of YER 1,500 (£4.50) per person each way, plus YER 2,000 (£6.00) on food per day for the family.

Half of the patients found the clinic fees at the Centre reasonable or cheap compared with the private sector; however, half found the cost of transport, subsistence in Sana'a, private sector tests and non TB medication difficult to meet. A few patients had not expected to pay for medication and expressed the state should provide free treatment. Some patients struggled to fund the multiple elements of diagnosis added to clinic fees. Even patients with a *regular income* had concerns about the cost of diagnosis, healthcare and medication, particularly as private healthcare and treatment could run into thousands of rials.

Patients not completing diagnosis reported expenditure on clinic fees of YER 300 (£0.90), private blood tests of YER 2,000 - 4,000 (£6 - 12.00) and non TB medication of YER 4,500 - 5,000 (£13.40 - 15.00). One patient was aware of having been overcharged and paid YER 2500 – 3000 (£7.50 - £8.90) for sputum tests and YER 200 (£0.60) in unofficial payments to staff. Like those that completed diagnosis, several patients found the clinic fees reasonable compared with the private sector<sup>Q1</sup>.

Q1 *“Your charges are really good and cheap - even the poor can afford it. For example in [name] hospital, the X-ray costs 1,400, but in your centre it is really cheap - just YER 50. [...]That’s only regarding the tests, like the saliva test and the X-ray, but I have no idea about the [cost of] medication.”* (Young, female patient, did not complete the diagnostic process, IDI)

The total cost of diagnosis was unaffordable for a few patients who reported higher costs from private tests and non TB medication<sup>Q2</sup> and, in one case, overcharging and payment of bribes to Centre staff. A young male spent YER 4,000 (£12.00) on a test in a private laboratory, which he found expensive. Another young male on a low income was referred for tests outside the Centre and given a prescription for medication.

Q2 *“they only gave me the prescription note and I had the tests done outside the centre. [...] The difficulties I faced were ... financial as I had to pay for the medication and the taxis - and I was not familiar with the area. I paid 4,000 for the tests and 5,000 for the medication.”* (Young, male patient, did not complete the diagnostic process, IDI)

### Overcharging, underhand payments and preferential treatment

The majority of patients completing diagnosis stated they had not been overcharged or asked for extra payments nor witnessed others being defrauded. Two patients expressed patients were treated equally and that no preferential treatment was given for friends of health professionals or in exchange for extra payment<sup>Q1</sup>. This was unlike the corruption they perceived was prevalent in other health institutions<sup>Q1</sup>. A minority of patients witnessed instances of financial irregularity<sup>Q3</sup> and felt that this behaviour might dissuade patients from returning to the Centre<sup>Q2</sup>, and one noticed that patients with a personal connection in the X-ray laboratory were seen first<sup>Q3</sup>. Patients attending focus group discussions who had completed the diagnostic process alluded to the fact that corruption among officials is widespread in Yemen<sup>Q4</sup>.

Only two patients not completing diagnosis mentioned professional impropriety among staff. This comprised overcharging and requests for illicit payments for one patient<sup>Q5</sup> and preferential treatment for another<sup>Q6</sup>.

Examples of equal and honest treatment of patients by staff:

Q1 Husband: *"Nothing wrong everything is fine. Nothing like the other hospitals where those people who facilitate the job for you for a cost [offer help, but expect something in return]!"*

Patient: *"It is the same. They treat the patients equally. No matter if that's a friend or that pays money or so [...]"* (Young, female patient, completed the diagnostic process, ID1)

Examples of overcharging, underhand payments and preferential treatment:

Q2 Son: *"Listen sister, for me it's not a problem, I can afford [it], but I noticed if the patient gives YER 100 to pay for a YER 50 service, the cashier won't give the 50 change, despite it is there in the till! What does it mean?"*

Son: *"It is a matter of principle. Fifty ryals is nothing, but when you collect 50 from hundreds of patients that are (sic) a lot and not acceptable. Some patients prefer not to come back again because of this treatment [...]"*. (Son of older, female patient, completed the diagnostic process, ID1)

Q3 *"[...] I noticed one negative point... [...] at the X-ray it works with connections. We had to wait there for a long time there at the X-ray. [...] Not only me, many patients were waiting there but those with connections were allowed in. [...] I noticed there were too many staffs. All were trying to get you a ticket. I felt as if they work for themselves. [...] For me, I got a receipt, but I noticed others were not issued with tickets. More than one member of staff asks the patient to pay money and the*

*patient ends up paying more than he should!"* (Young, male patient, completed the diagnostic process, IDI)

Q4 Interviewer: *"The services are available in every district all over the country, to provide the diagnostic process to everyone."*

Patient: *"And the corrupt officials are in everywhere as well!"* (Male patient, completed the diagnostic process, FGD)

Q5 *"now staff meets you in the corridor and ask you to pay 200 rials. When I asked my dad [who accompanied a family member 20 years ago] he said: 'That is unlawful'. I asked him: 'Were you charged then?' He said: 'No. This money goes to their own pockets.' [...]*

*"When you walk in, they just approach you [and] start asking: 'What do you need?' and walk you to the doctor room or the lab and in the middle of the corridor they ask you to pay 200-300 without knowing what it is for! They collect it from you at the corridors." [...]*

*At least if there's a receipt you will understand what it is for! [...]*

*It is bearable when they scrap the food [free food parcels], but to be asked by the staff members to pay bribes - that is horrible!! Those who do the checks [tests] are really nice people, but those who are in the corridor are really bad. I don't know what their job is [whether they] are doctors or something else, I do not know! [...]*

*"[I] went upstairs for the phlegm test, but was charged higher than any other private lab. [...] I am not sure how much I paid - approximately 2500-3000! [...] When you ask them why it is that expensive and higher than the private ones, they reply to you very rudely: 'Okay, go out and check with them!' They are supposed to be cheaper because they are funded by international bodies."* (Young, female patient, did not complete the diagnostic process, IDI)

Q6 Interviewer: *"What about the waiting time? Did you have to wait long to see the doctor?"*

Patient: *"No, I didn't wait because of the help I had by that person."*

Interviewer: *"Was it a crowded place did you notice any crowd?"*

Patient: *"Yes too many people were there."*

Interviewer: *"You feel that they were waiting for their turn to be seen?"*

Patient: *"Yes, some of them wait for their turn, but others walk in because they have connection in the centre."*

Interviewer: *"It means those who have connection in the centre they just jump the queue?"*

Patient: *"Yes. I walked in because I had that person who helped me."* (Young, female patient, did not complete the diagnostic process, IDI)

## **Enablers and barriers for attending and completing diagnosis**

### *Financial, economic and work factors*

Some patients completing diagnosis indicated they were able to afford clinic charges, transport costs, the additional private diagnostic tests and non TB medication, foodstuffs and subsistence costs in Sana'a, including, on occasion, accommodation. Others had put money aside, or been assisted by family members, neighbours, work colleagues and friends. Assistance included a loan or

donation for transport costs or clinic fees, the offer of overnight accommodation and the provision of food.

Examples of patients with financial resources included a retired patient who met the diagnostic costs, hired a car and bought food from a buffet and a young, unemployed male who was accompanied by his cousin/brother-in-law and said that *“He did everything [for him]”*, by assisting him financially, inviting him to stay and providing food.

Patients not completing diagnosis reported fewer enabling financial factors, with only a few patients citing instances where their economic or work situation had facilitated their attendance. These included two patients without major financial constraints; including an elderly patient who had travelled 100 km by taxi with his family and had stayed in a hotel, and a patient supported by a family friend who worked in the Centre and covered the diagnostic service charges. The vast majority of patients not completing diagnosis, however, were hindered by financial, economic or work factors. Half put forward financial constraints as a major barrier, of which transport costs constituted a significant part<sup>Q1,2</sup>. Several patients also highlighted the cost of private tests and medication as the main constraint<sup>Q2</sup>. One patient believed that being faced with unexpected private sector prices could put patients in an embarrassing situation<sup>Q3</sup>. For another patient the cost of transport compounded by private sector costs was prohibitive<sup>Q4</sup>. A few patients found work and other commitments made it difficult to complete the diagnosis<sup>Q5</sup>.

Examples of financial constraints:

(Patients not completing diagnosis, IDI)

Q1 *“Moneywise, if I could afford it I would have returned; but it is too expensive. Can you imagine it costs YER 1,000 to go to the Centre? It’s a long distance and costs a lot. [...] If I could afford it I would go, because my health is more important [...]”* (Young female patient)

Q2 *“The difficulties I had faced were more financial, as I had to pay for the medication and the taxis - and I was not familiar with the area. I paid 4,000 for the tests and 5,000 for the medication. [...] The only problem I had was when asked to get the medication from outside the Centre, from private pharmacies and it is unaffordable; especially with my humble salary, which is YER 30,000 only! [...] It is very expensive to go to the private labs and I cannot afford it. [...] I decided not to come back*

*again, as long as it is not very serious and especially, I cannot afford to come back again...” (Young male patient)*

Q3 “[...] some patients cannot afford the tests at a private centre. It is very embarrassing to the patients when they find it expensive, if they cannot afford [it].” (Young, female patient)

Q4 Patient’s father: “[...] We can’t afford all this money for transport and medication. [...] The tests and medication had to be obtained from outside the centre and that is expensive. [...] The blood test cost me 2,000 and the medication 4,500. That is too much! [...] It is not easy to go every day and to buy from private places. If you give the medication in the Centre, the transport cost is easy to afford.” (Male patient)

Example of work constraints:

Q5 [...] “[I] gave all my time for the centre. I wanted to finish it all in one day because I was busy and did not want to come back again. [...] I was busy with my work and I can’t take two days off. In so far as the test results come out within 30 minutes, I preferred to finish it all in one day [...].” (Male patient, did not complete the diagnostic process, IDI)

Some patients completing diagnosis had also clearly struggled to meet the costs of diagnosis<sup>Q7</sup>. An unemployed patient found it difficult to meet transport costs, despite living in Sana’a. Another was unable to work and described the cost of medication and travel as high, despite residing nearby and paying a taxi fare of YER 500 (£1.50). These patients were forced to make decisions on arrival about which elements they could afford and some decided not to purchase the prescription<sup>Q7</sup>, to borrow money<sup>Q6</sup> or ask friends and family for assistance. Some had little margin to meet unexpected costs<sup>Q6</sup> or to make arrangements to cover work, household or farm responsibilities or their children’s care. For example, a retired soldier from Yareem (south-west highlands) had been in Sana'a for 5 days, found everything expensive and was short of money. He tried not to smoke or chew Qat and had left his children behind to look after themselves. An older male had not anticipated needing so much money and had to delay his diagnosis for one day while additional money was sent from his village. Some better-off patients suggested factors that might inhibit attendance or completion by others; namely, the cost of accommodation, since most patients came from outside Sana’a, and financial constraints.

Some patients completing diagnosis found it problematic to leave their work<sup>Q8</sup>; either because it was difficult to obtain permission - especially paid leave - from their employer, or because they were

self employed. Some patients (in particular females) reliant on family members to accompany them were delayed because of the relative's work commitments<sup>09</sup>. Others found it difficult to leave home and family responsibilities, for example a patient had to leave her children while she attended the Centre and her elder son had to ask for work leave.

Example of unexpected costs:

Q6 *"I was shocked when they asked me to pay for the medication. I thought its state funded. I had to borrow some money to pay for my medication. [...] Some others lent me some money and I topped up. [...] [The next day I came early] to collect my free medication card. I don't have money but I did not get it like the others. I left home in the early morning and got there but did not get that card. I was brushed off, given a prescription and told to return in 2 months. [...] Financially, I was told you get a card with which you free medication paid by the government. [...] The staffs should be more helpful and merciful with us and ask about our financial situation if it was poor they should give free medication. It is supposed to be state funded. They should take into consideration our situation and not say to us go now come back tomorrow, try this and come back later...this way is not nice is it? They should save your life, you give injection, prescribe you medication ask how you are? Have you got some money old man? And if you say I am in financially difficulty he (doctor) should give you free medication as it is not out of his pocket, it's government money."*  
Older male patient, completed the diagnostic process (IDI)

Example of referral for private tests and medication:

Q7 A female patient was referred outside the TB Centre for a blood test:  
*"[...] those who cannot afford it find themselves in a very bad situation. Another difficulty is the transport. To go outside the centre to the nearest lab you need at least 300 rials to pay for the taxi, if someone was asked to go to the lab and he did not have enough money to pay for the taxi, he would not return! This is one of the difficulties."*

The patient did not purchase the prescribed medication:  
*"[...] I told the doctor: 'I have to go for my prayers now. I will buy it [the medication] later.', but I did not."* (Patient, completed the diagnostic process, IDI)

Example of subsistence, travel and opportunity costs:

Q8 Son: *"We pay a lot of money to come to this centre. Some patients come from a very long distances. Some come from ALHADA, some come from THAMAR. It cost them YER 7,000 each way, that's YER 14,000, plus another YER 7,000 for your expenses in Sana'a, which means YER 21,000. [...] Now I take from my annual leave and I spent too much money - 7000-8000 ryal. Just for this two day trip around 35,000. And the centre is located on a hill and it is very tiring to come up and down the centre. You need YER 400 just to pay for the taxi shuttle! [...] The centre is located on a hill and the taxi drivers exploit us. [...] I am an employee and [the] days off I got are deducted from my annual leave, which I supposed to take it to have some rest or go on a holiday. In top of that, it is deducted from my salary. Plus what I spend here - over 7,000 a day - which means in the five days I spent over 35,000."* Older female patient, completed the diagnostic process, IDI)

Example of waiting for a companion:

Q9 Son: *"She was ill for over a month in the village and we were late because I was busy here [in Sana'a]."* (Older, female patient, completed the diagnostic process, IDI)

### *Physical factors*

Some patients completing diagnosis indicated they resided close to the Centre, which kept transport time and costs to a minimum. Some had relatives in Sana'a who had provided overnight accommodation and some owned, or had access to private vehicles. Others however, indicated distance to the Centre was an important barrier. Several patients had travelled from distant cities for two to five hours. Some patients had difficulty walking<sup>Q1</sup> and took public transport for short distances, while others walked to the Centre because they did not have money. A young male coming from Rada'a (2 hours away) felt one of the reasons patients may not return was the long journey<sup>Q2</sup>. The patient observed that the majority of patients attending the Centre came from outside Sana'a and accommodation was a problem. The patient stayed in a hotel, but commented others could not afford this. Many FGD participants also indicated the most important barriers were transport<sup>Q3,4</sup> and travel related cost<sup>Q3</sup> and the difficulty of overnight accommodation<sup>Q4</sup>.

Examples of physical constraints:

(Patients completing diagnosis)

Q1 *"It's painful. It's the beginning of the (sic) death."* (Older female patient, whose diagnosis lasted 5 days, IDI)

Q2 *"Some other barriers can be personal circumstances, the accommodation or the financial situation."* (Young male patient, IDI)

Q3 *"the transportations are the main issue - if you do not have money you will not make it to here. I paid over 3000 just for the transportation."* (Patient, FGD)

Q4 *"It is difficult to find transport or to stay over for two nights"* (Patient, FGD)

One patient not completing diagnosis came from outside Sana'a (Madbah), while the remainder came from the city or its outskirts. Despite few living far away, several spoke of a long and difficult journey and of the physical difficulty of attending due to their illness<sup>Q5</sup> and, in one case, pregnancy.

For two patients, the journey (and in one case the accompanying cost) was a key reason for not returning to the Centre.

Example of physical constraints:

(Patient not completing diagnosis)

Q5 “[...] [the] transport side was very tiring and difficult; I had to come from Biir Obid. From here [TB Centre] to our house it’s hectic and difficult. [...] [It was] tiring. [I] felt short of breath.” (Female patient, IDI)

#### *Psychological and social factors*

A few patients completing diagnosis had been advised to attend the Centre by friends and family, some of whom had attended before. These included an older female patient who trusted the Centre, as her mother had attended herself and recommended it. A small minority of patients expressed they had been hindered by anxiety, stress and uncertainty about their eventual diagnosis.

Patients not completing diagnosis reported fewer supportive psycho-social factors. One young man, however, acknowledged the moral support received from his brothers, which he considered more important than financial support<sup>Q1</sup>. A young male wished all doctors would behave like those working in the Centre and felt well cared for, finding the doctors competent and honest<sup>Q2</sup>. A female patient found that familiarity with the site, thanks to a visit 12 years earlier, had helped her to find her way around.

Examples of psychological and social enablers:

(Patients not completing diagnosis)

Q1 “to be honest brother, [...] the moral support is more important than the financial support”. (Male patient, IDI)

Q2 “As prophet Mohammed said: ‘May Allah bless a man [the doctor] who did his job perfectly’”. (Young, male, IDI)

### *Gender-related and cultural factors*

Patients completing diagnosis expressed gender-related enablers and barriers. Female patients were concerned about being seen by a male X-ray operator<sup>Q1,2</sup> and one was pleased that the X-ray operator had been female the day she attended. Females participating in the FGDs did not find their husbands or male family members had obstructed their access to diagnostic services. One patient nevertheless gave a graphic example of the treatment of her mother when she fell ill, which suggested her family held strong views about her illness<sup>Q3</sup>. Another presented late to health services because she had to serve and look after her uncle<sup>Q4</sup>. Some females agreed that some families prioritised the health of boys over girls and did not seek healthcare for girls. After giving the matter some thought, male FGD participants also agreed with the facilitator's prompt that females faced more difficulties to attend<sup>Q5</sup> and that females would need permission from their father, husband or brother, whereas it was easier for men to attend on their own<sup>Q8</sup>. One male patient considered rural women would be hampered by lack of travelling experience and would not have access to household finances<sup>Q6</sup>. Some male patients agreed that females might be concerned about neglecting their duties at home and that some men might prevent their wives from leaving the house for this reason. There was however acknowledgement that preventing women from seeking medication could have disastrous consequences and even result in death. Some expressed strongly that men were responsible for the health of female relatives<sup>Q7</sup> and failure to seek healthcare for them was a result of illiteracy and ignorance.

Examples of gender-related enablers and barriers:

(Patients completing diagnosis)

Q1 *"To have a female X-ray operator for the female patients and a male operator for the male patients that would be better."* (Female patient, FGD)

Q2 *"[...] if you can segregate the female patients from the males and the X-ray operator to be a female for the female patients."* (Female patient, FGD)

Q3 *"In the past when my mother fell sick, she was locked in and they would only give her food through the door and lock it again. Then when her mother decided to take her to the hospital, she was [...] tied up on a donkey, she was so weak."* (Female patient, FGD)

Q4 *"I live with my uncle. I was coughing for a very long time, but he did not bring me - only once or twice. But when my father came back, he took me to the hospital from the first cough. I served and looked after my uncle."* (Female patient, FGD)

Q5 *"it must be difficult for them [women to come to the health centre] because they need transportation and an accommodation to stay overnight."* (Male patients, FGD)

Q6 *"It is very difficult for the ladies. [...] If they have to come from the countryside they will need an accommodation and they do not know how to move around the capital cities, and they cannot afford the expenses of three to four days."* (Male patient, FGD)

Q7 *"The man is responsible to treat her or even to sell all what he owns, to fund her treatment."* (Male patient, FGD)

Q8 Patient 1: *"[...] some [men] do not even believe in medicine and if their sons tell their dads about the importance of the hospitals, they just say: 'No, let her die at home'."* [...]

Patient 2: *"They [men] only realised at a very late stage, when it's too late!"*

Patient 3: *"Some [men] just do not want to know."* (Male patients, FGD)

Several females not completing diagnosis encountered difficulties specific to women. Two female

patients found it problematic to attend, since they were dependant on a family member to

accompany them<sup>Q10</sup>. One was waiting for her brother and presented late<sup>Q10</sup>, and the other was

constrained by childcare responsibilities, pregnancy and having no-one available to drive. A male

patient commented that it was difficult for women and children to follow the diagnostic process<sup>Q11</sup>.

Similar to patients completing diagnosis, female patients found it embarrassing to have chest X-rays

with a male operator and to share the X-ray room with males, although some were pleased to

report same sex staffing<sup>Q9</sup>. One female was asked to change in a rush and felt uncomfortable.

Examples of gender-related and cultural enablers and barriers:

(Patients not completing diagnosis)

Q9 *"My husband told me if the x ray staff is a male I rather you die at home than doing it!"* (Patient and interviewer laugh). [In fact the patient was seen by a female]. (Female patient, IDI)

Q10 *"[...] there were some difficulties. Even when I went to the Centre, the lady there asked me: 'Why were you late to come up, if you had the cough for long?' I told her [because of] the transport and my brother is always busy, and I can't go there alone. I have to have someone with me - my brother, for example. [...]"* (Female patient, IDI)

Q11 *"For me I am fine, but there are women and children. It is really, really difficult for them."* (Male patient, IDI)

*Returning for a second day and reasons for abandoning the diagnosis*

Several patients completing diagnosis stated they had returned for the second day because staff had asked or convinced them and they understood the need to complete diagnosis for their own benefit<sup>Q1</sup>. Among the difficulties faced for returning for a second day, patients mentioned the need for accommodation, transport and subsistence costs and the physical effort involved in returning to the Centre. A particular issue was being unaware of the need to return; associated with a lack of understanding of the smear microscopy process<sup>Q2</sup>. An older male, for example, felt that the diagnosis could have been completed in one day, as the doctor did not seem to have much to do<sup>Q2</sup>.

Examples of enablers and barriers for returning for a second day of diagnosis:

(Patients completing diagnosis, IDI)

Q1 *"If it is necessary for the job to be done properly, that is fine."* (Patient's son)

Q2 Interviewer: *"Why [was it] difficult [to return]?"*

Patient: *"Because the second day test was not needed and the doctor could have done it in the first day. He was free. He was FREE! He had nothing to do."*

Interviewer: *"He could've dealt with you there and then?"*

Patient: *"Not just myself, but 10 more patients as well!"*

(Older male)

Several patients completing diagnosis proffered possible explanations why others might fail to return. These included having limited financial means, the logistics of travelling from outside Sana'a, tiring of the diagnostic process<sup>Q4</sup> and, for those that could afford it, turning to private healthcare<sup>Q3,5</sup>.

Examples of hypothetical reasons for abandoning the diagnostic process:

(Patients completing diagnosis, IDI)

Q3 *"I rather to pay (sic) 20,000 for a private test outside the centre than wasting my time here. Imagine if you work for a private company and you are off work all this time?"* (Older, female patient)

Q4 *"There is a shortage in the doctors in this centre. I have seeing [seen] some patients suffering in [on] the ground and there's no doctor to see them. Some get upset and leave the centre without being seen by doctors!"* (Older, male patient)

Q5 Son: *“those who can afford [are] going to private hospitals. [...] Those with limited resources come to this centre.”* (Older, female patient)

The many reasons given by patients not completing diagnosis for abandoning the diagnosis and not returning for the second day are presented together, since they are tantamount. As patients that completed diagnosis had hypothesised, cost and work<sup>Q10,12</sup> were key barriers, as well as turning to, or being referred to, private healthcare providers<sup>Q12</sup>. Some, however, mentioned the expense of tests and non TB medication in the private sector as inhibiting factors<sup>Q7,8,9</sup>. Some patients lacked understanding of the need for further testing and sputum submission, in common with patients that completed<sup>Q11</sup>. A female was hindered by pregnancy, childcare responsibilities and having no-one to bring her to the Centre<sup>Q13</sup>. One elderly patient not completing diagnosis was not required to return to submit sputum in person, as he was old and ill and resided 100 km away. His granddaughter brought the specimen one week later. Otherwise, the reasons given were quite distinct, centring on receiving test results the first day.

Nearly half of participants in this group had received negative smear results<sup>Q13</sup> and/or were told they were *TB negative* the first day<sup>Q6,12</sup>. Some were diagnosed as having ‘allergy’<sup>Q6</sup> or ‘(mild) infection’<sup>Q12</sup> and two had received prescriptions<sup>Q6,9</sup>. One patient receiving a negative first-day smear had consulted a private doctor and another had been referred to a private clinic. A few patients understood from the doctor that their condition was not serious<sup>Q9</sup>; one of whom had been given a ‘clear lung’ result<sup>Q10</sup>. Three patients stated they had not been asked to return<sup>Q8,10</sup>. Two males (one elderly, one young) were unable to produce quality sputum the first day and were registered as defaulters, although they had returned to submit specimens several days later<sup>Q11</sup>.

Examples of barriers to return the second day and reasons for abandoning the diagnostic process:

(Patients not completing diagnosis, IDI)

Q6: The patient received a negative result, diagnosis and prescription the first day and consulted a private practitioner:

*“[...] they said come the next day [...] but I did not come back. [...] the doctor in the Centre told me that I only have a kind of allergy. He said that I am clear from the TB. [...] when the result was negative and [I was told] it’s only an allergy, I felt happy. [...] when they told me: ‘You are fine’,*

*that's why I did not come back again. [...] He gave a prescription [...]. I went to another doctor and he told me that I am not having that disease [...]. He told me: 'You only have a kind of allergy and there's no need to go back.'* (Female patient)

Q7: Expense of tests and non TB medication in the private sector:

*"[...] it is very expensive there [at private laboratories]. I made blood test for 4000. That is too much! Honestly, just a blood test cost me 4000. Four thousand! I swear by Allah, 4000!"* (Young, male patient)

Q8: The patient was not asked to return and was constrained by private sector tests and medication:

Patient's father: *"He [the doctor] did not tell to come back again. We can't afford going there all the time - our financial situation is bad. [...] The only difficult thing is to pay for the medication from outside we cannot afford."* (Young male patient)

Q9: Cost as a major inhibitor for completing diagnosis. Patient was given a first day diagnosis and prescription and led to believe his condition was not serious:

*"The difficulties I had faced were more financial, as I had to pay for the medication and the taxis. And I was not familiar with the area. I paid 4,000 for the tests and 5,000 for the medication. [...] they only gave me the prescription note and I had the tests done outside the centre. [...] The only problem I had was when asked to get the medication from outside the centre from private pharmacies and it is unaffordable - especially with my humble salary which is YER 30,000 only! [...] It is very expensive to go to the private labs and I cannot afford it. [...] I was diagnosed with something mild, [...] a fibrosis. [...] they only told me: 'You have some infection' [...]. He [the doctor] did not remind me to come. I decided not to come back again in so far as it is not very serious and especially, I cannot afford to come back again... [...]"* (Young, male patient)

Q10: The patient understood his condition was not serious and was not asked to return:

Patient: *"When I went there in the early morning [I] was seen by the doctor and the doctor told me: 'Your lung is clear.'"*

Interviewer: *"But he [the doctor] did not ask you to come back again?"*

Patient: *"No, because I did the two tests - the phlegms and X-ray - in the same day and gave all my time for the Centre. I wanted to finish it all in one day, because I was busy and did not want to come back again. [...] I was busy with my work and I can't take two days off. Since the tests results came out within 30 minutes, I preferred to finish it all in one day. On top of that my condition was not that serious."* (Young, male patient)

Q11: The patient was referred to the Centre for treatment. He had expected to receive medication, but was asked to repeat smear microscopy. He did not understand why the hospital were not recognised at the Centre. The patient was unable to produce quality sputum for 2nd and 3rd specimens and was asked to submit further sputum samples.

*"I was supposed to get the medication straightaway. Because they have all the test results and all details they should just give me medication. They said: 'We will give you a three days medication only - Thursday, Friday and Saturday.' [...] until the tests results came out. They did not trust the tests which were taken in the [name] hospital! [...] Because they wanted to make sure that I was positive, they checked all the tests results and everything, but were not sure[. They were] confused."* (Young, male patient)

Q12: The patient was not asked to return, received a negative result or diagnosis, was constrained by work and other commitments, and understood his condition was not serious:

*"I was not asked to go back [for a second day], but heard from some patients only. [...] The commitments and work - plus the doctor told me: 'Do not worry, you are negative. It is only mild infection. [...] If it was something serious, I would have gone back again. [...] I felt a bit ill after that and went to Al-Zahrawi centre and was given this medication. [...] I feel better [after taking the medication] praise be to Allah. As Allah said: 'There is a cure for all disease'. Doctors are only means for treatment."* (Young male patient)

Q13: The patient received a first day negative smear and was constrained by pregnancy, childcare responsibilities, distance and having no-one to accompany her:

Interviewer: *"Were you asked to come back in the next day for a second test?"*

Patient: *"Yes, but I told them I can't, because I live far. I have children. But anyway the result came out negative! [...]"*

Interviewer: *"What prevented you from going to the centre in the next day?"*

Patient: *"What prevented me from going there? First of all I was not quite sure if it was TB or not. Second point I was pregnant and the long journey and the burden of the transportation! My husband was ill in bed and there was no one to drive me there. I only had my mother, but she is too old to take me there."* (Young, female patient)

Vignette illustrating public-private referral, the financial burden of the process and its impact on patient healthcare choices:

The patient had spent a lot of money on healthcare before attending:

*"then [I] went to the TB centre and they could not get me any remedy at all. They only asked me to avoid some foods [such] as fish, eggs ..."*

She was given a negative diagnosis on the first day:

*"we waited for thirty minutes, then the X-ray and the saliva test result came out. Then [we] went to the chest doctor and he told me: 'You only have infection' and asked me to visit him in his clinic. [...] And the result came out negative. [...]"*

*It was very expensive at the clinic and I could not complete the treatment there. I was asked to pay 1,000 for the test, then was asked to do blood test and [an]other for YER 2,400. And I did not have that money and I had already spent all what I had. I told him: 'Ok, I will be back', but I did not. It has been a month now!*

*I started taking my sister's medicine and I went to her doctor. My sister is asthmatic [...] it's for the cough. She is asthmatic, but her condition is worst than mine. [...] Once I had a very bad chest pain, then she gave me one of her tablets and I felt better after taking it. I do not take it very often, only if I was not feeling well. This doctor is my sister's friend. She does all the tests for free because we are in [financial] hardship. I am contemplating to go back to see the doctor, because he told me not to go to the Centre, only to see him at his clinic. But, I cannot afford it now.*

*To be honest moneywise, if I could afford it I would have returned but it is too expensive. Can you imagine it costs YER 1,000 to go to the Centre? It's a long distance and cost a lot. It is too tiring and*

*too dusty. If I could afford it I would go, because my health is more important [...]"*  
(Patient not completing diagnosis, IDI)

### *Sources of support*

The majority of patients completing diagnosis cited receiving support. Many patients were accompanied by family members, including children, siblings, spouse, parents and extended family. These members provided financial assistance, moral support, advice on health seeking, and practical help such as completion of paperwork and physical care. A mother of 10 children had come from Harad - a 5 hour journey - and was assisted financially by her married eldest daughter, who lived in Sana'a, and by her 11 year old son, who earned money by selling Qat. The patient had been accompanied by her daughter during the diagnosis. Several patients however were constrained by a lack of support, stemming from unemployment or lack of finances within the family, vulnerability and isolation as refugees and, in one case, a lack of concern by family members. Absence of support resulted in delayed presentation and difficulties in meeting diagnostic costs.

Although patients not completing diagnosis received less material support from others in the form of financial assistance, overnight accommodation and food and drink, half had been accompanied to the Centre and the majority felt psychologically supported by the family. Their companions were immediate and wider family members who had travelled with them. One patient was assisted through the first day by a family friend and nephrologist, who guided her and ensured she was given priority and paid the fees. Participants however also mentioned lacking support<sup>Q2</sup>, including being denied financial assistance from employers<sup>Q1</sup> and experiencing a lack of concern from a spouse<sup>Q3</sup>.

Examples of lack of support:

(Patients not completing diagnosis, IDI)

Q1 *"[...] I asked for some help from my [military] unit, but they declined my application."* (Young male).

Q2 *"no one supported me. I even failed to get the [free] medication on that day."* (Young male).

Q3 *“My husband was not bothered. He told me: ‘it is up to you if you want to go or not’. [...] Actually I was concerned about my unborn baby and my wellbeing and the children’s. My husband would say: ‘nothing wrong with you’”. (Young female).*

### **Patient understanding and report of diagnosis and diagnostic process**

Many patients completing diagnosis were unclear of the disease they had despite being prescribed medications. Some said they had been told to have ‘only infections’<sup>Q1</sup>; others described a diagnosis of ‘(acute) chest infection’<sup>Q2</sup>. While some patients were satisfied with this diagnosis; others wanted to know more<sup>Q3</sup>. Not all patients understood the meaning of negative test results<sup>Q4</sup> and some understood a negative first day smear indicated they did not have TB. Others were disconcerted by having a *clear* chest X-ray but positive smears. A minority of patients were confused by the diagnosis. A patient with extra pulmonary TB did not understand why he had not been referred for smear microscopy and why he had been prescribed treatment when the chest X-ray was clear. He insisted on having smear microscopy before agreeing to start the 6 month treatment.

A few patients gave a clear account of the steps involved in the diagnostic process while others clearly did not appreciate the rationale for taking repeated sputum samples or spreading sputum submission over 2 days, interpreting this as health service delay.

Examples of understanding of diagnosis and diagnostic process:

(Patients completing diagnosis, IDI)

Q1 *“[the doctor] told me that I only have infections.” (Older, female patient)*

Q2 *“[My daughter was diagnosed with] infection in chest.” (Mother of older, female patient)*

Q3 *“I wanted to ask him what is my illness. I want to know if it is TB or not? I used to smoke in Kuwait and the doctors are not very clear with us there.” (Older, male patient)*

Q4 *“No one asked me [to come the next day]. I was negative.” (Older, female patient)*

Approximately half of patients not completing diagnosis reported having an infection or a chest infection. Many patients who were recorded as not having TB or to be smear negative understood their condition was ‘not serious’ and ‘something mild’<sup>Q5-7</sup>. Several patients in this group were also

unclear what their diagnosis was, other than being informed that they were fine and/or had a negative first day smear test results, or in one case a 'clear lung' based on X-ray and smear results.

A young, male patient was not reassured by the doctor's diagnosis: *"[I] went back to him [the doctor] and [he] prescribed me with some medication following the test result. He told me: 'You are fine'. I told him: 'No [I] am not'. He said: 'Do you want to be ill by force?!'"*

Similar to patients that completed, there was confusion about the meaning of a negative test result and many inferred there was no need to return to the Centre: *"the doctor told me: 'Do not worry you are negative. It is only mild infection' . [...] I was relieved when the doctor told me: 'You are negative'."* One young male TB patient understood that he had a mild case of TB and therefore did not need to take strong medication and a male patient with smear negative TB receiving treatment at the Centre believed he had a chest infection alone as he had a negative smear result:

Interviewer: *"Were you diagnosed with TB?"*

Patient: *"I was told that I have chest infection only. [...] When I came here I showed them the reports I brought with me from the [name] hospital, I was told to do a phlegm test. The first was fine, the second was also fine - so was the third. I was told I had chest infection only. [...] praise to Allah, it [phlegm tests] showed negative [...] The doctor asked me questions and told me that I had fever and a cold."*

In common with patients that completed diagnosis, there was a lack of understanding about the spot morning spot scheme and the need to submit further samples. One young male regarded the request to return for a second day of tests as a product of staff error rather than routine practice and did not understand why further tests were needed<sup>Q8</sup>. Even patients that were well educated or had experienced TB in the family did not see the importance of returning to complete the tests.

Examples of understanding of diagnosis and diagnostic process:

(Patients not completing diagnosis, IDI)

Q5 *"[I] went to the TB Centre [and] was found negative. It was not TB, but mild infections".* (Young female patient)

Q6 *"I was diagnosed with something mild: 'You have a fibrosis'. [...] they only told me: 'You have some infection' [...]"*. (Young male patient)

Q7 *"then the x ray and the saliva test result came out. [...] And the result came out negative. [...] Then [I] went to the chest doctor and he told me: You only have infection'."* (Young female patient)

Q8 *"Because it too busy. That's why they ask you to come in another day. [...] I felt that they were not satisfied or (they) doubted the test results. [...] "They did not trust the tests which were taken in the [name] hospital! [...] they wanted to make sure that I was positive. They checked all the tests results and everything but were not sure[. They were] confused. [...] I was supposed to get the medication straightaway. Because they have all the test results and all details they should just give me medication. They said we will give you a three days medication only [...]. I was not happy when each doctor asks for new tests - that's why I felt they have been confused and they want you to start again from scratch. [...] As long as they have everything they needed - tests, x- ray - why they just did not give me the medication straightaway? But they asked for more tests and more syringe. I have the traces of syringes all over my body. Eight syringes in my back and each syringe is like a knife stab. [...] The staffs should be more helpful and not to waste patients' time. They just ruin all the previous tests. And the doctors should be more helpful as well, from the doctors and the staffs. [...] The doctors ask for new tests. [...] The time waster is not the staffs it's the tests and process, but as staffs they are helpful."* (Young male patient)

### Understanding of disease

The majority of patients completing diagnosis had heard of TB<sup>Q2</sup> but had limited understanding of the disease<sup>Q1</sup>. A few previously treated patients were aware of the symptoms, infection routes and severity of the disease, but had questions about disease causation and reoccurrence, extra pulmonary TB and the importance of following treatment regimens<sup>Q3</sup>.

Examples of understanding of disease:

(Patients completing diagnosis, IDI)

Q1 *"I did not ask him [the doctor] because I knew what I had was because of the dust in my work. I did not even know about the TB. [...] Even if I had the chance to ask him, but I knew I am not having TB it is only because of the nature of my job the paint and the dust that's all."* (Male patient employed as painter and decorator)

Q2 *“Actually, I knew about the TB long time ago from experience with one of my neighbours. We know that it is fatal if was not treated!”*

Q3 Questions about diet and treatment:

*“But when I asked the doctor he was busy because the room was crowded. But I asked and claimed information from different sources but it has [to come] from a specialist. I asked what could happen if it was not treated immediately and what kind of food that boost the body immune [system].”*  
(Male patient)

Male patients participating in FGDs felt only a small proportion of the population had awareness of TB and would recognise its symptoms. Some patients had been made aware of the disease through a television campaign operated by the NTP. Others found out about the disease and its symptoms when attending the Centre. A young female patient had not heard of TB, while another had had the disease before and was aware of the symptoms. Although some patients had some knowledge of TB being infectious and its mode of transmission, others were unaware:

*“I would like to know where did the TB come from. [...] If I woke up well not having this disease, then I found myself suddenly not feeling well after going to school.”* (Young, male patient, FGD)

Two patients not completing diagnosis had knowledge of TB and self-referred. One had been treated 12 years earlier and one had had other cases in the family, including her husband. Despite their experience, neither patient returned to complete the diagnosis. Others had no previous experience of the disease and were unclear of the causes of TB<sup>Q4</sup>, even in the case of a patient diagnosed with TB who believed he was clear of the disease and was being treated for a *chest infection*.

Examples of understanding of disease:

(Patients not completing diagnosis, IDI)

Q4 *“actually I caught this disease from school. [...] The route to the school was so dusty and it is even called ‘the flour route’, because it is too soft. And I would trot and all this dust would go into my nose and mouth.*

*[...] even when you go to a doctor he asks you to keep away from dusts and smoke.*

*[...] because I was not paid, so I decided to leave the job. Then after that I thought it’s because of the dust. It’s not only me - even my colleagues are having some health problem because of the dust.”*

(Young female patient)

## Vignette

A young female patient had known many relatives with TB, beginning with an adopted family member whose entire family had died from TB:

*[...] all [her family had] died with TB [...]! Because in the village the awareness is very limited and they try to treat it by having eggs and honey! Her two sisters died with TB. No one sent them to be treated in hospital! Then we decided to bring her to live with us, because we are from the same big family. My father took her to a hospital and [she] was cured in less than a year. That was 20 years ago.*

The patient's husband became ill:

*"Then my husband fell sick and they suspected typhoid, his condition worsen he would take typhoid doses one after another but no progress we would take him to private hospitals and I suspected TB and asked him to go the TB centre but he refused to go... [...] I was sure that he was having TB and he was not accepting that, until I told him go to the German hospital as it is an advanced hospital. But he did not want to go... I was upset and fell out with him and threatened to move to my parents'. Then he went to the TB Centre and was diagnosed with TB. He came home very pleased. Now he is on medication.*

The patient was pregnant and suspected she had TB, but did not complete the diagnostic process. She received a first day negative smear result:

*"[...] I was concerned about my unborn baby and my wellbeing and children. [...] Did not want to pass it to my kids I was concerned about their safety. [...] My husband would say nothing wrong with you. My mother asked me if you feel the same symptoms your husband had before, let us go and check. It appeared to be because of the pregnancy mood."*

The patient was aware of the infectious nature of TB and asked the doctor for how long the disease remained infectious after treatment:

*"I did ask him if it is contagious or not. He said you are at the safe side - he has been in medication for over a month now, just take care. I was a bit concerned about my children. I would not make him kiss them much - did not let them drink from his glass.  
[...] I was worried for my children safety. I asked the doctor about my husband's case, then when the doctor told me because he is in medication for over one month it is not contagious now, so I was relieved."*

The patient did not ask any questions of the doctor:

*"I learned and knew about the disease from my sister's experience with TB."  
(Female patient, did not complete the diagnostic process, IDI)*

## Stigma and impact of the disease on relationships

Male FGD participants completing the diagnosis discussed the social implications and consequences of the disease. Some agreed TB could restrict the sufferer's social life, as other individuals would

avoid contact. In addition, doctors advised restricted contact with family members to avoid spreading the infection. An older male expressed that: *“the social effects sometimes are worse than the illness itself”*, explaining that Yemen is *“a very illiterate community”* with little awareness of the disease. One male patient stayed away from school to avoid infecting colleagues.

Females attending FGDs talked more openly about the social effects of the disease, indicating sufferers might stay at home rather than seek healthcare, out of fear, shame, or lack of knowledge of where to seek help: *“Some patients get scared from the disease. They fear to face the truth and prefer to stay at home without seeking medication.”* Some had experienced social isolation from neighbours, family and work colleagues, with one saying *“my neighbours run away from me”* and another saying *“Some are concerned about their safety. Even my brothers stopped visiting me.”* Some females expressed their husbands had not rejected them. A woman, who had to stop breastfeeding due to the illness had passed the illness to her son and said that in spite of this: *“[...] we were living as normal with my children and husband”*; while another described that her *“husband was very lenient and did not stay away.”* One female patient however, found the disease had a negative impact on her relationship with her husband. One female patient was asked to stay away from work, as colleagues were concerned about her coughing: *“If it happened that I coughed at my colleagues, they would step back from me and then I was told to stay home until I get well. [...] Then I felt that they were concerned, I had a one week sick leave. Then asked me: ‘What is your condition?’ I told them it is only infection. [...] even when I cough at my manager’s office he walks out!”*

Patients were asked their views on the possible effect of having TB on a person’s marriage prospects. A single female felt that: *“it does not mean that they [the fiancé] won’t accept you forever, but until you recover”*. Some women hypothesised that less literate men might break off an engagement. Some female patients expressed that having TB had not had a detrimental effect on

their self-confidence and felt that TB was nothing to be ashamed of as *“it does not last forever - it is curable”*:

*“It is not a stigma. We have to face it and cure it.”*

Male patients' views varied<sup>Q1</sup>. Some believed someone engaged would not inform his/her fiancé(e); others felt it would be better to first seek treatment; while others felt it was immoral to turn the other party away because of the illness.

Example of impact of illness on marriage prospects:

(Male FGD participants, completed diagnosis)

Q1 *“It would be better if they seek treatment first then have some recovery period, then to start any marriage plans.”*

*“The fiancé if was TB positive, he should be given sometime to seek treatment and if he did not get any better he should end up the engagement”.*

*“If someone proposed to my daughter, I will ask him to seek treatment first, then to come back again. [...] Just not to make him more sad. [...] It would be a disaster if we refuse him.”*

### **Health seeking behaviour**

A few FGD participants who completed diagnosis had previously been treated for TB, including one female who had not completed treatment due to pregnancy.

Patients reported consulting multiple healthcare providers before coming to the Centre at considerable expense, for example one patient spent YER 10,000 on a CT scan in a private hospital to obtain a diagnosis. These included doctors, hospitals and pharmacists. Some had attended local healthcare centres and found there were no diagnostic facilities. Others reported having been misdiagnosed. Some with previous experience of TB had self-referred to the Centre, while others were referred by healthcare providers. Many had attended the Centre due to its reputation. A male patient, for example, had consulted a local health facility in Al-Hada, but concluded that they did not have diagnostic facilities as there was no specialist doctor or X-rays. He preferred to come to the Centre, as he had heard it was the leading centre for TB in the country.

### **Additional views of patients registering for treatment**

Participants that registered for treatment had similar socio-economic backgrounds to patients that completed diagnosis. Participants were for the most part appreciative of the service provided, although they would have preferred diagnostic services to have been more accessible across the country. Many patients were relieved to have been given a diagnosis, having been unwell and concerned about their ill-health, and having spent a considerable amount of money consulting many healthcare providers before reaching the Centre. They described similar barriers for collecting treatment as patients described for accessing diagnostic services, namely: distance and transportation from home, physical exertion, transport and opportunity costs, lack of female independence and leaving responsibilities at work or home. Like patients that completed diagnosis, they recommended decentralising treatment services, as described in the DOTS programme and reducing frequency of treatment collection.

### **Suggestions for improvement**

Suggestions to improve the diagnostic services at the Centre included extending opening hours, employing additional doctors, stepping up measures for containing infection, providing extended waiting areas with seating, improving information-giving and ending petty corruption. Patients recommended extending the range of facilities to include the provision of beds and food, enhanced laboratory capabilities to undertake blood tests within the centre, better equipment, computerised records and an in-house pharmacy. Patients also suggested structural changes to service delivery and diagnosis, calling for a same day diagnosis, more accurate diagnostic tests, decentralised diagnostic, retesting and treatment services, the provision of a shuttle bus and even the introduction of a mobile clinic.

Participants in FGDs completing diagnosis suggested providing overnight accommodation, a shuttle bus for transportation from the city centre and hospital beds to facilitate patient attendance at the Centre. Patients suggested opening additional Centres to cater for the high patient numbers and decentralising services so that patients could obtain a local diagnosis: *"If you can provide better*

*facilities in the rural areas so the patient will find no need to come to the main cities.”* (Patients, completed the diagnostic process, FGD).

Patients emphasised the need to raise awareness of diagnostic services outside Sana’a and of the Centre itself: *“[...] some patients waste their time and money moving between hospitals. Why you don’t make kind of publicity on TV and radio and on the newspapers to help them to come to this [centre] from the first place?”* (Patients, completed the diagnostic process, FGD).

Other suggestions included having a CT scan, segregated X-ray facilities and planting green spaces around the site. Male patients had ideas for educating the public about TB including passing on health information via imams, schools, local councils, print media and radio and door to door visits: *“It would be more useful if the imams at mosques raise the awareness about TB, then people will spot if they have any family member has caught this disease.”* (Male patients, completed the diagnostic process, FGD).

#### Synopsis: main barriers and enablers

In summary, patients gave a variety of reasons for defaulting diagnosis. These included receiving negative smear results the first day, clear X-rays, information from clinicians which suggested they did not have TB and inability to produce sputum. Many indicated that financial constraints (in particular the expense of private sector tests and medication), distance, physical ill-health or pregnancy, and religious and cultural norms concerning the position of women in Yemeni society impeded completion of diagnosis. Many patients completing diagnosis also reported difficulties to return the second day, citing poor health, loss of earnings, financial constraints, the need to tend to duties at home and the problem of overnight accommodation. Therefore, the vast majority of patients were hindered by financial or work concerns, which caused some to drop out of the process, elect not to collect prescriptions or to pursue a private sector referral. In addition, patients demonstrated a lack of understanding of the smear microscopy process, which threatened successful completion.

Factors which facilitated patients' attendance and completion of diagnosis included geographical proximity, having the financial means to attend, secure employment with the possibility of obtaining paid leave to attend diagnostic or treatment services, access to a private vehicle and a supportive network of family and friends. Key drivers to attend were also placing importance on one's health, motivation to receive a correct diagnosis and be cured, or the desire to protect other family members from the illness. While some patients emphasised that responsibility to complete diagnosis lay with the individual, others suggested that support and encouragement from doctors, more information and follow-up calls would encourage patients to return.

### **Discussion**

This is the first qualitative study to document barriers to accessing TB diagnostic services in Yemen. The study enrolled a large number of women, men, young, elderly, rural and urban patients to provide a cross section of different population subgroups. Although it is unusual in this society to elicit patients' opinions of services, participants gave both positive and critical viewpoints about diagnostic services and identified a plethora of obstacles to attendance. There are very few reports of qualitative studies on health issues in Yemen (Al-Iryani et al. 2010; Basaleem and Amin 2011; Busulwa et al. 2006; El-Jardali et al. 2010; Geyoushi et al. 2003; Hossain and McGregor 2011) and these focus predominantly on obtaining the views of stakeholders, the general public and health staff, rather than service users and thus the study is unique in this environment. As shown, the study methodology elicited complementary information to the quantitative surveys presented in previous chapters and their future use should be encouraged.

### *Service delivery*

Some patients found diagnostic services efficient in seeing and processing patients, waiting times and the standard of care reasonable, and were appreciative of obtaining a diagnosis. This view was not unanimous, as others found the facilities and staffing inadequate, the Centre overcrowded, disorganised and unhygienic, staff unprofessional and negligent of infection control, waiting times lengthy and the service disrupted by power failures, holiday closures and restricted opening hours.

Some patients were referred to private laboratories which increased waiting times. Although waiting times for smear tests and X-ray results ranged from 15 minutes to 2 hours, which is short in relation to most TB laboratories, patients had differing expectations about what constituted an acceptable wait. Some reflected that extending the Centre's opening hours would facilitate travelling home on the same day.

Only a minority of patients felt they had received adequate health information and felt free to put questions to health staff. Most patients thus had unanswered questions and many patients were unsure of their diagnosis. Doctors were perceived to be busy and to rush consultations. Clinics were also held very publicly and were found to be intimidating.

#### *Economic cost of attendance*

Most patients indicated direct and indirect costs for diagnosis and treatment were onerous. The main cost components of diagnostic attendance were the clinic fees, tests, transport, medications, loss of earnings and consulting other healthcare providers. These findings are similar to those previously reported by studies in other settings (Kamolratanakul et al. 1999; Kemp et al. 2007; Lonroth et al. 2007; Rajeswari et al. 1999; Wyss et al. 2001). Similar to the findings described in the quantitative surveys described in chapter 4, the most important expenses were transport, miscellaneous costs and clinic fees. Transportation is reported in the literature to be a significant barrier to accessing diagnosis (Cambanis et al. 2005a; Karki et al. 2007; Kemp et al. 2007; Othman et al. 2012; Umar et al. 2012; WHO 2005; Wyss et al. 2001) and reflects the considerable distances travelled by many patients. That said, some patients residing in Sana'a also found local transport burdensome, as they had to travel from their residency to the city perimeter and then take a taxi to the top of the hill where the centre is located. These costs and the effort of travel proved prohibitive for some patients who suggested providing a shuttle service. Transport costs were also a problem for patients who had registered for treatment, as transport for drug collection was arduous and patients often negotiated with clinic staff to attend weekly or less frequently to collect their pills.

Transport costs were followed by a set of unspecified costs and clinic fees. The former comprised tests conducted in the private sector, prescriptions, unofficial payments (often requested in return for faster delivery of test results) and Qat acquisition. Although clinic fees are fixed, reported charges varied considerably and it is likely some patients were overcharged. While some patients found the clinic charges reasonable compared with the private sector, some were aware of patients that could not afford these fees. Even though clinic fees appeared to account for a relatively small proportion of patient expenditure when compared with the cost of transportation and private sector costs, clinic charges have been reported to be a barrier to accessing diagnosis in other settings (Ramsay et al. 2010) and their discontinuation could improve access (Meessen et al. 2011). For many patients therefore, it was the combination of clinic fees with other cost elements which proved obstructive.

As in other settings, many patients reported borrowing money to cover the cost of attendance for diagnosis (Cambanis et al. 2005a; Cambanis et al. 2007; Rajeswari et al. 1999; Ukwaja et al. 2012) and some accumulated debts. Similarly patients had seen a reduction in income due to partial or total inability to work induced by illness (Kamolratanakul et al. 1999; Lönnroth et al. 2010b; Mauch et al. 2011; Wyss et al. 2001) and others had lost their jobs through repeated absences.

Interestingly, despite a large proportion of patients having to travel and spend the night away from home, very few had paid for accommodation and food, staying most commonly with relatives or friends, as previously described in this setting (Ramsay et al. 2009).

In conclusion, in Yemen the principal cost components (e.g. transport, clinic fees, private tests) often resulted in patients borrowing money and becoming indebted. Patients also feared loss of jobs and work-related income and experiencing stigma; particularly women. Although most studies in the literature report overall expenditure as a result of illness (Kamolratanakul et al. 1999; Rajeswari et al. 1999), they less frequently report costs separately for attendance at diagnostic services, as opposed to pre attendance and treatment costs, yet these costs are significant for patients and an important barrier to accessing diagnosis.

### *Support and companionship*

Most patients were accompanied by one or more friends or relatives, or by a work colleague or neighbour. The surveys reported in chapters 4 and 5 had described that the majority of Yemeni patients had attended the clinic with company and that this characteristic was more frequent in Yemen than in Ethiopia, Nepal and Nigeria. Many patients were given moral support and encouragement to attend diagnostic services and to take medication, while family members took care of children and household affairs, and assisted materially or financially. Accessing diagnostic services and treatment for many, therefore, was a group endeavour, as the whole family was involved in financing healthcare, accompanying, providing transport and collecting medication. Women in particular received many forms of support, since they are seen as dependent within a traditional societal role. Notwithstanding, many patients felt unsupported. Family or peer supervision is recognised internationally as a key element to ensure treatment adherence and completion (WHO 2006). Community treatment supporters, many non-relatives, are often recruited to oversee treatment and encourage adherence. As diagnostic support seems to play a significant role in Yemeni society, with its close-knit family and tribal ties, future work could explore the expansion of the role of diagnostic supporters to create community *champions* who promote diagnostic adherence.

### *Women's access to healthcare*

Neither male nor female patients spoke easily about gender differences to access healthcare; perhaps because male-female roles are well defined in this conservative society and founded on religious principles. With some prompting and discussion, however, there was acknowledgment that it was more difficult for females to attend diagnostic services, since they lacked autonomy to travel, to make independent decisions about their health and access household finances.

Conventionally, women require the permission of a senior male member of the family to attend a health centre (OECD 2012). It is also expected that intimate healthcare should be provided by same sex members of staff, which is rarely the case in the study centre and provokes anxiety among

women. Lastly, women would find it hard to leave their duties at home and some presented late to diagnostic services. Some males acknowledged that men would not necessarily seek healthcare for their female relatives.

#### *Awareness of TB, diagnosis and services and healthcare choices*

Many patients knew of someone who had or had had TB and many had previously been treated. Several patients believed that they had contracted TB from, or passed the infection to, a family member and some were aware of the need to take measures to avoid spreading infection. Many patients did not have a clear understanding of the logic of the diagnostic scheme and the need for repeated tests. Others were also unclear of the diagnosis received or the need for retesting during treatment. Some patients were unaware of smear microscopy services outside Sana'a, or of closer TB referral centres in Taiz and Hodeida. Others, who had registered for treatment in Sana'a, were not aware of the option of transferring out for treatment nearer home.

Much has been written about the health seeking behaviour of TB sufferers, delay in attending diagnostic services and the considerable patient costs incurred along the way (Lönnroth et al. 2010b). Study participants mirrored this trend and patients continued to move between different providers during and after attendance for diagnosis. Patients who completed diagnosis hypothesised that patients with money may prefer to seek private healthcare and consequently do not return to complete smear microscopy. Therefore, similarly to reports in the literature, patients often seek private healthcare and mix and match public private services (Khan et al. 2000; Lönnroth et al. 2010b; Sagbakken et al. 2008b; WHO 2005, 2011b). In this case, some defaulters turned to or were referred to the private sector, including the private clinics of the Centre's staff.

#### *Acceptance of disease and degrees of stigma*

TB patients made different choices about who to inform about their disease. These ranged from informing selected members of the household, informing neighbours and work colleagues and class mates. These decisions are often influenced by concerns of generating stigma and segregation by peers and relatives (Armijos et al. 2008; Liefoghe et al. 1995; Lönnroth et al. 2010b; WHO 2005).

Although some considered that there would be no negative effect of disease disclosure on their relationships and believed they had a duty to inform them, others moved to the city to avoid the stigma prevalent in rural communities and withheld their disease status at work or school, believing they might lose their place. Patients held mixed views about whether or not to inform a fiancé(e) or postpone marriage plans and women are known to be particularly vulnerable to rejection by a husband or fiancé if they contract TB in this society (Date and Okita 2005; OECD 2012).

### Summary

Our findings therefore confirm that key barriers for diagnosis are clinic costs, transportation and distance from home. Although TB treatment is free in Yemen (2008), the financial impact of transportation costs (Ramsay et al. 2009), clinic fees, private laboratory charges for supplementary tests and loss of earnings on patients, is great. Public transportation in Yemen is expensive and not always available and the terrain is difficult and mountainous (McLaughlin 2007). Although Yemen has implemented a decentralised DOTS service (2008), which aims to increase accessibility for patients, it seems most patients still consider the current locations for diagnosis and treatment too distant for submission of samples and daily collection of medicines. This qualitative study provides an explanation as to why attending the clinic with company is associated with higher patient expenditure, as found in the survey reported in chapter 4. Patients' stories illustrate that the majority attended with at least one and often several companions, who while playing a valuable supporting role, equally multiplied transport, subsistence and opportunity costs. Being accompanied is a prerequisite for a family to authorise female attendance at a clinic (OECD 2012). It is likely that the association of rural or other town residency with higher expenditure (reported in chapter 4) is linked to the cost of transportation, which accounted for the most significant part of patient expenditure and is higher for patients from outside Sana'a. Barriers to patient attendance and completion of diagnosis in this context therefore support the description of these barriers in the literature (Storla et al. 2008) and highlight the need to locate diagnostic and treatment centres as close to the community as possible (Wei et al. 2008).

The manner in which patients reacted to costs was dependent on their ability and readiness to pay and expectations. Some patients faced multiple barriers to attending the diagnostic centre, such as unemployment, illiteracy, absence of schooling and social isolation - indicators of multi-dimensional poverty. The Somali refugees interviewed appeared particularly vulnerable, speaking of hunger and were further isolated by not speaking Arabic (Lönnroth et al. 2009).

Another finding of the study is the requesting of additional payments by staff. Similar problems are often observed in other high burden countries (Okeibunor et al. 2006; WHO 2005), but the problem is difficult to quantify and staff often object to their reporting. The study however had taken place before the political changes that occurred in Yemen in 2011, after which many senior management staff were dismissed on charges of corruption and the problem may be controlled, at least within the Centre. In depth interviews with staff also indicated senior management were aware of the problem and were trying to rectify it.

Another issue that is rarely discussed in this society are gender issues, which are key to ensuring accessible services. Yemen is a traditional male dominated society, deeply religious and was for many years under a conservative government. Males have freedom of movement and control the household income, while women are housebound and consult males for most family decisions. It is not known whether women who attended the services are representative of all women contracting TB, as it is likely some women never attend the services. TB diagnostic services therefore need to consider the differential female access to services and devise diagnostic approaches that are acceptable in this society and ensure accessibility by all.

## **Conclusion**

This qualitative study provided a unique opportunity to explore the views of Yemeni patients on the facilitatory and inhibitory factors for attendance at diagnostic services and treatment registration, in a country in which the perspective of patients on health services has rarely been heard. Northern Yemen is characterised by its conservative Muslim and tribal society and the study required some adaptations, particularly with regard to the operation of male and female interviewers, the

organisation of FGDs and appropriateness of interview questions. The study was successful in interviewing defaulters from diagnosis, thus providing an interesting complement to the quantitative survey, which only included patients that returned to complete the diagnosis process. It also provided explanations for the higher expenditure of patients from rural areas or other towns and the detail of unspecified costs; issues which were left unanswered in the survey. As intended, the use of two different research tools provided differing information. The FGDs allowed the differential experiences of men and women in accessing healthcare to surface, as well as the impact of disease status on social and work relationships and opinions on public awareness of TB.

The access barriers for completion of diagnosis (and eventual treatment registration) which were particularly prominent, and in some cases unique, to the study setting, were the relatively frequent practice by clinicians of providing patients with a first day clinical diagnosis and often a prescription; reports by several patients of overcharging, requests for unofficial payments and preferential treatment by staff and the elevation of costs to the patient through a system of referral to the private sector for additional tests. It was evident that female patients faced particular and multiple barriers to attendance in this context, in which the majority of women play a traditional and subservient role in public and private life. These included lack of autonomy to travel, to make decisions, to access household finances, lower levels of education and disease awareness and narrowness of experience due to a restricted lifestyle. These restrictions inevitably also impacted on women's ability to participate fully in the research. It is likely that many women do not attend formal health services and studies in the community are necessary to further explore the unique situation of women. The study also revealed that the majority of patients attending the health centre had several companions and inflated costs, patients continued to use private healthcare during and after attending diagnostic services, and that fairly high levels of stigma surrounding TB prevailed in Yemeni society.

The particular vulnerability of Somali refugees and the heightened difficulties faced by rural residents, for whom distance, cost and physical effort were more acute, due to the centralisation of TB diagnostic services, were highlighted.

These issues convey difficult access to TB diagnostic and treatment services, which would have been exacerbated by the political conflict that affected Sana'a after completion of fieldwork in 2011.

## Chapter 7

### Exploring barriers and enablers to accessing TB diagnosis and treatment in southern Ethiopia

*"I said that I have finished telling my story, not that the story is finished. I said before that no story is ever really finished, each one is part of a longer story and consists of smaller stories, some of which are told, others passed over in silence. And whenever you tell any one of the stories, whether you intend it or not, you include the shadow of all the others. The result is that once you have told one story, once you have undone the meshes of the net at one point, you are trapped. You are compelled to go on with the story. And because we ourselves, like all life, are stories, we become the story of the stories."*

— Herbert Rosendorfer, *The Architect of Ruins*

#### Introduction

Ethiopia, in the Horn of Africa, is a country with a high burden of tuberculosis. In adults, the disease is the most common cause of hospital admission and the main cause of infectious death (Ethiopia 2007). Despite an expansion of the DOTS programme in the last decade, the case detection rate remains low and a substantial proportion of the estimated cases are undetected by health services (Yassin et al. 2006).

Although both Ethiopia and Yemen's populations are poor, there are large differences between the countries. The majority of Ethiopians follow the Christian Coptic Church, only a sizeable minority are Muslim and a larger proportion of the population reside in rural areas. Ethiopia is also known for its cultural diversity and nowhere is this more apparent than in the Southern Nations, Nationalities, and Peoples region (SNNP) which, as its name suggests, has the largest variety of tribes, cultures and languages (Briggs 2005). Thus, socio-cultural barriers to access and complete diagnosis are likely to differ between these two countries, although the effects of poverty may be experienced similarly in both environments.

The DOTS programme in Ethiopia was initiated in the 1990s, with financial support from the Italian Cooperation; officially reaching 94% coverage in the Southern Region by 2004 (Yassin et al. 2006).

Although the Programme in this Region performs better than in other regions and reports an ever increasing number of cases, case detection remains low. Access barriers are likely to play a key role

in contributing to the low detection rate, alongside other barriers such as limitations of available diagnostic tools and prevalence of HIV and MDR TB, by deterring many patients from completing formal diagnosis.

The Southern Region, situated within the Rift Valley, is one of the largest regions of Ethiopia and has an estimated 14 million population. Awassa, its capital, is the second largest city in the country, with a population of about 150,000 inhabitants. Its small size compared with the total population of the region reflects a predominantly rural settlement.

Government health service provision is increasing (Ethiopia 2007), but remains insufficient for the population. Seventy five percent of the population is rated by the government to have *good access* to health services; however good access is defined as residing within 15 kilometres of a health facility. Roads and public transport are limited and thus certain populations groups, especially those who are poor and live in remote locations, are less likely to access diagnostic services. The risk analysis presented in Chapter 4 confirmed that rural or other town residency, low education, illiteracy, being accompanied at the time of consultation and certain occupations such as being a farmer, student, housewife or labourer, were factors associated with high costs for accessing diagnostic services. Like Yemen, variables independently associated with high expenditure were rural or other town residency and attending the clinic with company (74% patients were accompanied).

The qualitative studies presented here were conducted among patients attending health facilities in proximity to Awassa. These included IDIs and FGDs of male and female patients that completed the diagnostic process and patients who registered or had failed to register for treatment. They were designed to explore in more detail service perception and the barriers confronted when accessing services, and to complement the quantitative information presented in chapters 4 and 5.

### **Methodology**

The study methodology in Ethiopia followed the standard protocol set out in the general methodology chapter, with some variations described here.

Adults aged > 18 years were selected from a logbook of TB suspects attending Awassa and Bushullo Major Health Centres during the study period (September 2009 to July 2011) and invited to participate in IDIs or FGDs. The research team, comprising a male social scientist and two social workers (one female and one male), were trained in qualitative research methods and conducted interviews with patients completing diagnosis and registering, or failing to register, for treatment. All individual and group interviews were conducted on site, with the exception of IDIs with patients not registering for treatment which were conducted in the patients' homes. Data collection was overseen by the local co-ordinator through collation of transcripts and discussion of the study progress at team meetings.

Interviews were conducted in Amharic, sometimes with the assistance of a companion to translate from the patient's mother tongue. The vast majority of interviews were recorded digitally; however a few IDIs and one FGD were recorded by hand, according to the preference of research participants. The social scientist and social workers transcribed in Amharic from the audio recording onto laptops. A professional translator from the University of Awassa was employed to produce a written translation from Amharic to English, which was sent back to the local project co-ordinator for checking.

#### *Tracing TB patients*

Two weeks post interview, the researchers phoned the respective Health Centres to establish whether or not the TB patient had registered for treatment or not. For those patients that had not registered, the team visited the District Health Office and introduced themselves to the TB and Leprosy coordinators for the district and health centre and the district supervisor of the Health Extension Workers (HEWs). The Health Centre TB Unit register was checked and names of TB patients who were not registered given to the TB and Leprosy Coordinator for the *woreda*.

#### *Number of IDIs and FGDs conducted*

Fifty IDIs and 6 FGDs were obtained with patients completing diagnosis; 21 IDIs and 3 FGDs with patients registering for treatment; 2 IDIs with TB patients diagnosed with TB choosing not to register

for treatment and no IDIs with patients defaulting from diagnosis. Three IDIs were excluded due to concerns over quality and 3 FGD transcripts were mislaid.

### *Presentation of findings*

Focus Group Discussions with patients completing diagnosis provided particularly rich information with respect to the barriers faced by women, health information giving by staff, the social stigma surrounding TB and reasons for defaulting from diagnosis. Patients registering for treatment interviewed individually were especially informative about prevailing social attitudes towards TB and patients not registering for treatment shed light principally on the reasons behind their decision not to register and also material assistance received. In relation to other issues, participants' views concurred with patients completing diagnosis taking part in IDIs and therefore the results are not presented separately.

## **Results**

### **Characteristics of participants**

The study comprised 50 IDIs with participants completing diagnosis, of which 22 had attended Awassa Health Centre and 28 Bushullo Major Health Centre on the outskirts of Awassa. Fifteen were female and 35 male with an age range of 18 to 70 years, as shown in Table 7.1. Thirty-five participants resided in an urban and 15 in a rural area. Six FGDs were conducted with patients in this category. No IDIs were secured with patients defaulting from diagnosis.

Twenty-one IDIs and 3 FGDs were conducted with patients registering for treatment. Among IDI participants, 8 were female and 13 male with an age range of 18 to 50 years, as shown in Table 7.2. Sixteen participants resided in urban and 2 in rural areas. The FGDs were conducted among male and female-only and mixed participants, and their main characteristics are described in table 7.3. In depth interviews were conducted with two male TB patients not registering for treatment, aged 35 and 70 years, married with children, living in the countryside; the former selling chat and the latter living off his land.

**Table 7.1. Characteristics of IDI participants completing the diagnostic process**

<b>Sex (M/F)</b>	<b>Age (years)*</b>	<b>Rural or urban</b>	<b>Sex (M/F)</b>	<b>Age (years)*</b>	<b>Rural or urban</b>
Female	18	Urban	Male	35	Urban
Female	21	Urban	Male	38	Urban
Female	23	Urban	Male	40	Rural
Female	25	Urban	Male	48	Rural
Female	33	Urban	Male	50	Rural
Female	40	Rural	Male	50	Urban
Female	42	Urban	Male	65	Urban
Female	47	Urban	Male	Old	Urban
Female	54	Urban	Male	25	Urban
Female	70	Rural	Male	47	Urban
Female	40	Rural	Male	24	Rural
Female	38	Urban	Male	Young	Urban
Female	Old	Urban	Male	24	Urban
Female	Young	Urban	Male	Old	Urban
Female	Young	Urban	Male	Young	Urban
Male	18	Rural	Male	Old	Rural
Male	18	Urban	Male	Young	Rural
Male	20	Urban	Male	Old	Urban
Male	22	Urban	Male	Young	Rural
Male	25	Rural	Male	Young	Urban
Male	27	Urban	Male	21	Rural
Male	30	Urban	Male	21	Urban
Male	30	Urban	Male	36	Urban
Male	31	Rural	Male	30	Urban
Male	35	Rural	NA	NA	NA

\*Age <35 was categorised as young; where age was not specified in years. NA = not available

**Table 7.2. Characteristics of IDI participants registering or not registering for treatment**

<b>Registered (Y/N)</b>	<b>Sex (M/F)</b>	<b>Age (years)*</b>	<b>Rural or urban</b>
Y	Female	25	Urban
Y	Female	20	Urban
Y	Female	20	Urban
Y	Female	32	Urban
Y	Female	Young	Urban
Y	Female	18	Urban
Y	Female	Old	Urban
Y	Female	Young	Rural
Y	Male	50	Rural
Y	Male	20	NA
Y	Male	45	Urban
Y	Male	30	Urban
Y	Male	38	Urban
Y	Male	30	Urban
Y	Male	Old	Urban
Y	Male	Old	Urban
Y	Male	Young	Urban
Y	Male	Old	Urban
Y	Male	26	Urban
Y	Not known	NA	NA
Y	Not known	NA	NA
N	Male	35	Rural
N	Male	70	Rural

\*Age <35 was categorised as young; where age was not specified in years, NA = not available

**Table 7.3. Characteristics of FGD participants completing the diagnostic process**

<b>FGD no.</b>	<b>Sex (M/F)</b>	<b>Age</b>	<b>Rural or urban</b>	
<b>1</b>	Female	Young	Urban	
	Male	Young	Urban	
	Female	Old	Urban	
	Male	Old	Rural	
<b>2</b>	Female	Young	Urban	
	Male	24	Urban	
	Female	38	Urban	
	Male	36	Urban	
	Male	22	Urban	
<b>3</b>	Female	25	Urban	
	Female	28	Urban	
	Male	34	Urban	
	Female	65	Urban	
<b>4</b>	Male	18	Urban	
	Female	19	Urban	
	Male	20	Urban	
	Male	60	Urban	
	Male	38	Urban	
	Male	40	Urban	
	Female	18	Urban	
	Female	25	Urban	
	Female	30	Urban	
	Female	40	Urban	
	Female	35	Urban	
	<b>5</b>	Male	32	Urban
		Male	32	Urban
Male		28	Urban	
Male		18	Urban	
Female		29	Urban	
Male		32	Urban	
Female		18	Urban	
Female		45	Urban	
<b>6</b>	Male	63	Urban	
	Female	37	Urban	
	Female	60	Urban	
	Female	28	Urban	
	Female	40	Urban	
<b>7</b>	Female	32	Urban	
	Female	40	Urban	
	Female	24	Urban	
	Female	35	Urban	
	Female	26	Urban	
	Female	37	Urban	
	Female	18	Urban	
	Female	38	Urban	

**Table 7.4. Characteristics of FGD participants registering for treatment**

FGD no.	Sex (M/F)	Age (in years if known)	Rural or urban
1	Male	20	Urban
	Male	26	Urban
	Male	26	Urban
	Female	28	Urban
	Female	37	Urban
	Male	45	Urban
2	Female	18	Urban
	Male	24	Rural
	Female	25	Urban
	Male	35	Rural
	Male	36	Urban
3	Female	Young	Urban
	Male	Young	Urban
	Male	Young	Urban
	Male	Old	Urban
	Female	Young	Rural
4	Male	18	Urban
	Male	24	Urban
	Female	24	Urban
	Female	25	Urban
	Male	28	Urban
	Male	36	Urban
	Male	40	Urban
	Male	49	Urban
5	Female	20	Rural
	Male	20	Urban
	Male	24	Urban
	Female	25	Urban
	Female	32	Rural
	Male	42	Urban

### Experiences and perceptions of diagnostic services

#### *Positive perspectives*

Patients that completed the diagnostic process at Awassa HC were generally satisfied with diagnostic services, finding the service to be efficient<sup>Q1, 3, 4</sup> (considering the volume of patients) and of good quality<sup>Q1, 2</sup>. Many found the service charges to be lower than in other health institutions.

Participants who were familiar with the Centre, either through a previous visit or living locally, remarked that its reputation had improved<sup>Q1-3</sup>, as it had had a poor reputation for many years.

Patients said they had experienced this improvement firsthand, finding a more pleasant health complex<sup>Q1, 2</sup>, improved staff attitude towards patients<sup>Q1-3</sup> and more efficient service<sup>Q5</sup>.

Examples of positive perspectives of diagnostic services (Patients completing diagnosis, IDI):

Q1 *"I received good service since Friday I started diagnosis. In the former time it was difficult to get service timely. Even to obtain card we used to queue up early in the morning. But now we obtain very soon, get diagnosed and receive the result [on Monday]. [...] Awassa Health Centre is better than any other health centre. The way they treat people and their hospitality is good. [...] They give service with love. [...] before they were not good, but now they welcome the patients and attend to people in good mood. So I am very thankful. [...] The health centre is improved and its treatment is better than that of hospital. [...] When I look at the compound it is changed. [...] now everything is clean, be it toilet or others. I think there is much improvement."* (Older male)

Q2 *"Starting from 2007 [...] this health station underwent a great reform in its organisation and staff. In general it's good. The requirements of the patients are met. [...] the process of examination at this health station is good and very pleasant. I found the health station by itself is comfortable. No more rudeness as before. [...] This makes me to affirm that the medical service I got here was pretty good. [...] there is [has been] a noticeable improvement. Since I am a frequent patient here I am able to see the difference."* (Young male)

Q3 *"I didn't see anything inconvenient compared to the previous situation. [...] When I come in this health centre before, it lacked many things. These were lack of cleanliness of the compound including a problem with the guard. The card room was too slow. Today everything is changed. It is good. [...] I will begin from the card room. There was no queue. I waited for my turn and they treated me fairly. This is good thing. Next I want the examination room. On my way I met one nurse and asked her and she took me to the place and showed me. There were not even 2 people in the examination room waiting for their turn. There the professional who examined me was patiently listening to me to assist me. So I was happy when I went out. She explained me everything about the disease and what I should do. When I came the laboratory it is good - everything is done smoothly. They treat everyone fairly and equally. I gave sputum yesterday in the afternoon. They told me to bring another one the next morning. Then I gave the sputum the next morning around 9 hour [3 p.m. European time] in the afternoon. They should be encouraged to keep it up. The service should be continued."* (Young male)

Q4 *"It didn't take me a long time. [...] My name was called according to my turn. I did not have any trouble with my card. The organisation is very good. [...] In the previous time it took longer time for the patient to get treatment. He may not get turn. Now the problem is solved and everybody goes home on time before lunch up to 6 o'clock [midday European time]. They will not come back in the afternoon. Maybe for the laboratory test result you may come back in the afternoon."* (Older male)

Q5 *"It depends on the number of the patients. There are a lot. Everybody must wait for their turn. Here the work is done properly. There is no skipping the queue or reshuffling or no unfair action. Everyone gets his turn in time. I came late and waited for my turn and treatment."* (Young male)

#### *Negative perspectives of diagnostic services*

Many patients were also critical of the disorganisation in the card room<sup>Q6, 7</sup> (and in one case the cashier's office)<sup>Q8</sup> of Awassa HC, complaining of a lack of an orderly queue<sup>Q8</sup> and patients pushing in

and being sent for examination in the wrong order. Personnel issues were another area of complaint, as some patients experienced staff arriving late<sup>Q13</sup>, not being in their posts<sup>Q12</sup> and having a poor attitude towards patients<sup>Q11, 12</sup>. Some patients questioned the practice of health officers who failed to conduct a physical examination. A few patients complained of a lack of hygiene<sup>Q9</sup>, particularly in the toilet areas. Some FGD participants considered laboratory and medical staff incompetent<sup>Q16, 17</sup> and had low confidence in the Health Centres<sup>Q14-17</sup>. Examples of incompetence involved staff losing specimens<sup>Q17</sup> and results<sup>Q16</sup>, failure to perform physical examinations<sup>Q15</sup> and give an alternative diagnosis for smear-negative patients<sup>Q15</sup>, and prescribing injections without taking blood pressure.

Examples of negative perspectives of diagnostic services (Patients completing diagnosis, Awassa Health Centre, IDI):

Q6 *“After I obtained my card from the card room, the cards were not in its sequence form. It was mixed up. The last comer [last to arrive] become the first, the first became last. This condition [situation] has taken us much time to get examination [...].”* (Young female)

Q7 *“I went in the card room. There were crowds of people there so I could not get the card on time. I stayed there for 2 hours; so the weak side I observed is the one in the card room. [...] they have no speed in treating people [...]. They should increase their speed and even if they lack workers, they should employ more.”* (Young male)

Q8 *“The weak point I would like to raise is that there are people who are out of order at the cashier when we pay for the medicine. There is pushing around and no waiting for their turn. In that situation there might be a thief who pretends to be a patient who comes to steal patients’ money, the disorder exposed for the thief [us to theft]. So to avoid this, the guards should take responsibility to keep order in lining up the patients like they did when I first came here. When we pay money, we should line up to pay to obtain medicine.”* (Young male)

Q9 *“I was upset because of one incident. One patient happened to vomit around the reception. Because it was not cleaned soon, it made all the patients to be disgusted. The patients passing by that area were forced to cover their mouth.”* (Young male)

Q10 *“After my coming to the laboratory room, it was difficult to stay for a week because the sickness gets worse. I was seriously sick. I have complaint on that [...]. When I reached laboratory on Wednesday, I was asked to come on Tuesday. I stayed for 7 days with my sickness. On Tuesday when I arrived there was no work. I received my result on Wednesday. That made me worry a little bit about my health. So I suggest that quick service should be given. [...] I was disappointed because of the length of the time. A person who is sick is eager to know about his sickness. He wants to receive treatment soon.”* (Young male)

Q11 *“Female nurses can be observed maltreating [patients a] little. There are some who do not have good relationship with customers [although] now this has decreased a little (...) there is maltreating and people are observing complaining [...]. [This] should be corrected.”* (Older female)

Q12 *“People who provide card should make good hospitality. They should care for the patients. First the patient is encouraged to have HIV test when he comes. From the laboratory I was sent to voluntary HIV examination service. When I reached there the health professional got angry and asked who sent me there. I was disappointed. [...] After he got angry he told to come in, but he didn’t tell me to sit down. I entered and stood and he took my blood for test after putting on his glove. He told me to wait for the result. Another examination is another [one examination is like another], but I say when you have HIV testing special care should be taken. That must be improved. The card room and laboratory people should be happy when they treat the patients. Though it is difficult to treat the patient who is sick, I say they must treat well. The patients face problem because the cashiers are not available. The patients face problem to pay the money to obtain medicine. I think these people should be in their place. [...] If everybody is in his place of work... Regarding the organisation, most of them are not at work. The organisation is good but all are not at work. It may be for another [a second] job.”* (Young male)

Q13 *“I have observed these points during my examination. First, the professionals are late. Instead of starting to work at 8:30 a.m., as it is the case in any government office, they start at 9:00 a.m.”* (Young male)

Examples of negative perspectives of diagnostic services (Patients completing diagnosis, FGD):

Q14 *“[...] I gave my sputum 20 days ago. After that my relative was sick and went to Addis Ababa. When I came back from there, I came here to know my result. When I asked laboratory section, they told me to go to the place where I was examined. Then when I came with paper, I was asked to go to the card section. It should have been to the examination room, but I was sent to card section [...]. Then I told sister that I am not newcomer [...]. After that she mistreated me. I went out with my paper, then I came back on Monday. [...] the problem begins from the card section. The card can be used for 6 months. When I gave her the card she just put it down. Mine is there but the name of others is called. I was angry and went in. My card was in front of her. I picked up my card and gave it to her. I told her that I was feeling sick seriously. When I said this to her, she laughed at me. I was to say: ‘What makes you laugh?’. I tolerated, because if I get angry in the morning I will get sick. Then I took my card and went to another section. In fact, there is a problem. This kind of problem happens at work. This is a bit different; why, here the sick people should be looked at. They should look at the paper in front of them and give immediate response. If she doesn’t have ability, why does she sit there? The result of my sputum came, so I told her to check and tell me. She didn’t react. [...] when I heard this health centre is changed in to hospital, I was very happy. We are all happy. Because of this I was there when it was inaugurated. After becoming a hospital, it should work like hospital. When we see it, it is not like hospital. Most women would rather talk than work. In every section they talk while the patients sit. While there is a patient who is seriously sick, they gather and talk. The patient suffers. When it is time, they leave the work. The patient waits for them without being treated. Because, of this, once I reported to a woman who was in charge of the health centre and she got angry with them. [...] There is more to be improved I think. [...] I will come back on Monday again. Still it makes me cough. However, it is good if medicine is prescribed for me.* (Female)

Q15 *They gave some medicine and told me that I had no tuberculosis. But to my experience in case of lung problem the doctor examines with medical instrument but they merely give medicine. I was annoyed a little bit with it. Though it is not my profession. I expected to be checked with stethoscope. If there is no tuberculosis, cold or pneumonia could be checked with stethoscope. So I was in doubt whether or not to buy the medicine that was prescribed for me. At last I bought it. I was told nothing about my disease. I was disappointed to buy the medicine.”* (Male participant)

Q16 "I was given medicine after that I could not move my foot, so I could not commute. After the result I was sent to the doctor. When I gave him the result he was talking to someone. He left the room and went to another place. I went there and gave him the [result]. I said to him, 'Here you are the result.' He said 'Did you give your sputum?' I said 'Yes. I was told it would be finished tomorrow. I gave sputum in the morning. They told me to come back at 9 o'clock.' 'When I gave him the result of my blood test?' I said 'I gave you'. He said that he did not receive it. I said, 'Doctor I gave you yesterday while you were talking to someone.' He said that he did not receive it and he said I would be responsible and I should bring it. Do you think I am a child and lost it on the road or I took it home? I said to him he wrote on piece of paper and sent me to the laboratory. The laboratory sent back the result to him. I was in doubt. How do I know whether it is mine or not? Then he saw the result of the blood and prescribed medicine. I took the prescription to the pharmacy to buy the medicine. The medicine required me one hundred birr but I did not have enough money with me, so I went home without buying the medicine." (Female participant)

Q17 "I have dissatisfaction with giving sputum. I first gave sputum. When you bring 2nd, 3rd they ask you to bring another 2nd, 3rd. I don't know why they don't take note and tick it when you bring it. Why do they ask us? They should register. I have question why it is not clearly registered. So I asked him that "Where did you put it? You know that I gave you." He tried to cover his mistake. Now again when I brought it, they asked me whether I gave the 3rd. They should register when they received. I have TB. But I am in doubt because they are not careful. When I bring the second which one this? When I bring the 3rd they again ask which one it was. I doubt whether they really know it was mine. The professionals who received the sputum are different. The 1st the 2nd and the 3rd sputum are taken by different professionals. However, what was given earlier was not put properly and this brings doubt on the professional's work." (Female participant)

### **Length of the diagnostic process**

The diagnostic process for participants lasted between 2 days and 1 week, with the majority of patients attending the Health Centres for two days (or 3-4 days when spanning a weekend/holiday)<sup>Q4</sup>. A few patients attended for 3 days if they were unable to submit sputum or were too ill to return the following day. Approximately half of patients completing diagnosis found the duration reasonable, with a few expressing satisfaction<sup>Q1</sup>. The latter expressed that health professionals were working hard and that the diagnostic duration was predetermined by the duration of the medical routine<sup>Q4</sup>. Some were aware that the diagnosis often takes longer than for other diseases<sup>Q3</sup> and that it used to continue into a third day<sup>Q1, 2</sup>. Others had mixed feelings and found the duration problematic<sup>Q7, 9</sup>. Views included the sentiment that workers should arrive on time<sup>Q8</sup>; that the process was difficult for patients coming from a distance<sup>Q5</sup>; that some parts of the service were inefficient and that a shorter process was desirable<sup>Q6, 9</sup>. Illness<sup>Q9</sup>, perceiving the private sector provided a better service and concerns about opportunity costs made the diagnostic duration

difficult. Some patients were appreciative that the diagnosis had been shortened from 3 to 2 days, but others found this disconcerting and were concerned about a detrimental impact on quality<sup>Q10</sup>.

Examples of positive perspectives (Patients completing diagnosis, IDI):

Q1 “[...] demanding to get the result on the same day cannot be practical. As long as things are not done here spontaneously, one has to wait until the professional duly accomplishes his task. In my case, I got my result according to the requirement of their profession. It’s good. I have nothing to complain about. [...] they did not give me tiresome appointments of 3 to 4 days. [...] According to our respective time of arrival, they gave us our result with good manner today at 3 p.m.” (Older male)

Q2 “In the previous time diagnosis took a lot of time. Now active work was done for me.” (Older male)

Q3 “The sputum test at the laboratory takes 3 days, had the test been for malaria or other diseases, I understand that I would have completed everything within a day. So I can say that it was fine.” (Young male)

Q4 “It took me three days [Friday to Monday] and I was already informed about it. [...] One who wants to be healthy would not be disappointed by minor routines. [...] Due time must be given in order to get the result; besides this, the lab technicians are human beings, and all government offices are closed during the weekend. As far as I am concerned, I got the necessary medication and I’m feeling better.” (Older female)

Examples of negative perspectives (Patients completing diagnosis, IDI):

Q5 “It makes you lose your patience. That should be improved. [...] The patient should go through the medical examination without delay. For example, I am from here and there is no problem. But there was somebody who came from Shashamene. The people who come from distant place face problems. So, it would be nice if they receive the result immediately.” (Young female)

Q6 “I would have been pleased if I complete everything within a day or even immediately after. [...] Soon after I came here, I was very scared when I was told that I should give sputum at that time and come back the next morning [2 day diagnostic process]. I had even decided not to come back again. [...] On that morning I came with having in my mind to get everything completed by that very moment[. When], when I arrived here, I was again given another appointment for coming back at 3 p.m. Such process instead of remaining permanently, needs to be improved. It is good to minimise the time and treat patients in a short time. This process might be the rule of the organisation. If it is not so, it should be improved.” (Young male)

Q7 “I felt uncomfortable with the speed of the process, which was pretty slow. I gave my first sample of sputum on Friday. Today is Monday and I still didn’t get my result [this morning] [...]” (Young male)

Q8 “[...] when I came, I respected my appointment time. Even I came two minutes early. If the service providers arrive early in the same way, I will finish everything and go home.” (Young male)

Q9 “I got examined in other place. I knew my result and came here. I faced a problem to get registered here for treatment. They told me that they would not accept the result [...]. I went back to the place where I was diagnosed before. The doctor [there] asked me whether I wanted to die. He asked me why I had not received the treatment. I came here and was diagnosed here again. It

*was found out to be tuberculosis by X-ray. I had examination here. I was able to receive treatment after 5 days. The patient could die in this situation. [...] When I reached laboratory on Wednesday, I was asked to come on Tuesday. I stayed for 7 days with my sickness. On Tuesday when I arrived, there was no work. I received my result on Wednesday. That made me worry a little bit about my health. So I suggest that quick service should be given. [...] After my coming to the laboratory room, it is difficult to stay for a week because the sickness gets worse. I was seriously sick. I have complaint on that [...]* (Young male)

Q10 *“What I saw different here is the possibility to give sputum before or after breakfast. I worry that the sputum after breakfast will not have value to find out the disease.”* (Young male)

#### *Waiting time at the card room and initial consultation*

Opinions about the waiting time to obtain a registration card were mixed, with some patients reporting that they did not queue for long and others complaining that the card room was disorganised and there was a long wait. Regarding the waiting time for an initial consultation, the majority of patients were satisfied, reflecting that there was little or an acceptable waiting time and patients were seen in turn. Only a minority reported the order of arrival was not respected, the consultations were too long and the process lengthy.

#### *Waiting time for tests and test results*

Positive views included a perception that the laboratory service was swift and there was little or no queue. Negative views included finding the laboratory overcrowded and one patient’s irritation at being misinformed by staff and waiting all day for a result that did not appear until the next day<sup>Q11</sup>.

Q11 *“Among the professionals working in the laboratory there seems to exist a noticeable individual difference. I wonder if some of them are just students on practice. On Friday, I was slightly upset because of an incident. After I gave my sputum, instead of telling me to go back home, the technician told me to sit and wait for my result. I waited and waited ‘til 5:30pm. Then, after all the workers have left out, he gave me a container in which I should give another sputum. I was about to tell him that during all this time I had my shop closed and if the situation happened to be so, that he would have given to me the container earlier, but I refrained myself from saying anything and went straight home.”* (Young male)

#### **Staff practice and attitude**

The majority of patients completing diagnosis gave a positive report of staff at Awassa HC, expressing that staff performed their job well, listened carefully and treated patients fairly, with due care and attention and a good manner<sup>Q1,5</sup>. Some patients remarked that staff attitude had

improved in recent years<sup>Q4</sup>; staff was willing to go beyond their call of duty and work through their lunch break to attend to patients in the queue<sup>Q2</sup> and were genuinely concerned for patients' wellbeing<sup>Q3</sup>. Some FGD participants registering for treatment felt encouraged by staff showing that they were not scared of having contact with them.

Many patients however gave mixed reports, stating staff attitudes were variable<sup>Q9</sup>. Negative accounts included staff's lack of respect for patients. Staff (particularly health officers, but also administrators and HIV officers) communicated angrily and treated patients poorly<sup>Q6</sup>. One patient was dissatisfied at not having a physical examination and another witnessed that no-one, patients or staff, had come to help a patient who had collapsed to the floor<sup>Q8</sup>. Several participants indicated staff arrived late, took long breaks and did not fulfil their duties<sup>Q9</sup>. There were fewer complaints about laboratory staff, other than staff taking personal calls and having poor blood taking skills.

While some FGD participants praised staff for their good care and attention, many reported experiencing or witnessing mistreatment of patients by laboratory professionals<sup>Q10</sup>, discrimination of patients by administrative, nursing and care staff in reaction to their physical appearance<sup>Q11, 17</sup> and marginalisation by doctors<sup>Q13-14, 16</sup>. Patients described doctors and nurses being curt and insensitive to TB suspects<sup>Q12, 14</sup>, requiring them to cough elsewhere<sup>Q7</sup> and sit at a distance<sup>Q12, 16</sup>. Those who were given a positive diagnosis were further ostracised by staff which feared infection<sup>Q13</sup>.

Examples of positive views of staff (Patients completing diagnosis, IDI):

Q1 *"I found her [the doctor's] approach very comfortable to me. She asked me number of questions and went as far as allowing me to say everything that came to my mind. She attributed me ample time and after each of my statements, she used to say: 'Then after?' I just left the room after exhausting all of my questions. I really appreciate her; I am so happy with the way she treated me."* (Young male)

Q2 *Health professionals] pay sacrifice including their lunchtime to pay attention to the patients."* (Young male)

Q3 *"the doctor who examined me was very concerned about my health. While she was giving me her good advice, she told me that that I should take a great care to my hypertension. She advised me just in a way a father does for his son. (Older male)*

Q4 *“this health station has underwent a great reform in its organisation and staff. In general it’s good. The requirements of the patients are met.”* (Young male)

Q5 *“As I saw in some health institutions mistreating, I did not see anything of this kind.”* (Older male)

Example of negative views of staff (Patients completing diagnosis, IDI):

Q6 *“In the examination room, the nurse that examined me has the feeling of anger [looked angry]. When she asked me and I made mistake, she talked to me angrily. I apologised to her and she examined me.”* (Young male)

Q7 *“there are some who are not good. There is a lady. I don’t know her name. When I came in, she said ‘What are you doing here? Why don’t you cough outside and come in? Don’t cough here’. She is a health professional [...]. I am annoyed with her.”* (Young male)

Q8 *“There is something not good I could say; I myself saw something. A person came for treatment and received treatment. There was nobody with him fell down. No one took care of him. No one was to talk to him. There was two boys sitting and watching him. I went close to him to see what was going on. I asked what happen to him. He was unable to talk. He had sore throat. When I asked him he said ‘Ah.....Ah.....Ah. I can’t speak’. I asked if he was hungry. He said that he was not hungry. ‘I can’t eat’, he said. I asked him with sign what happened to him. ‘I feel pain here. I ate 6 days ago.’, he said. I said ‘Shall I get you soft drink?’ He said: ‘I can’t drink it’. I am an Ethiopian and I couldn’t leave him alone, as he is poor like me, so I was sorry. I went to many places to get solution his problem. Many people mocked at me. One brown boy who works in the injection room cooperated. He told me to take him to the place where he received medical examination. I held his hand and took him to the examination room. When I told her she was sorry and wrote him memo to the administration. I couldn’t get the administrator for 4 to 5 continuous hours. The previous boy gave him glucose and told me to take him to the pharmacy.”* (Older male)

Q9 *“some of the workers are going out, while the patients are waiting for them. These people are not fulfilling their duties the way it should be. Some of them are also going out for tea, while the patients are still there. It was better to entertain patients instead of going out for tea. Even after tea they don’t come back in time. There are some health professionals who are entertaining patients in good manner and some of them go even late for lunch, waiting until all the patients complete their examination [...] some are good, but some are not treating well the patient. [...] the workers of the health centre are not coming to their working place in time. This is the problem.”* (Young female)

Further examples of negative views (Patients completing diagnosis, FGD):

Q10 *“[...] patients who come from different directions want their results soon after the examination, to return home; therefore they repeatedly ask for the result. In the meantime, I heard the laboratory professionals and the patients exchanging bad words. The patient may be in serious condition, so it is good if the professionals not ill-treat the patient.”* (Male participant)

Q11 *“Some people discriminate between two people by looking at physical appearance and dress. For example, there a person whom I know. He highly educated big person. When he is physically seen. He is then he said not keep his personal appearance around the card room. They were telling him to go away. They maltreated him. Later they could not look in to his face when they knew who he was. There is such attitude. I was looking at her when she ill-treated him. I was saying this girl made fun of him. While she was arguing with man, the doctor told her about the man. She was scared. So they should regard everyone equally whether he is fat or thin, white or black, tall or short.*

*[...] They are there to serve the patients, not to maltreat them. Anyone who comes here whether big or small, comes seeking help. Those who do this are people at the lower position. They are heard saying: 'Come in. Go out.' It would be good if these people get some advice [training]. (Female participant)*

*Q12 "I have been to [the] health centre for many times. I know Dr [name]. When I got sick with malaria, he treated me very well. Now he told me to sit 40 m away from him. I am surprised how his behaviour is changed. [...] I sat where he told me to sit. He stood up and examined me. He examined me on my left side, but I had pain in my right side. Then I stood up and said 'Dr, I feel pain here'. He told me to sit down harshly, away from him. I showed him the result of the X-ray. Then I told him that I feel pain in this side. He said 'Just sit down. If you knew your disease, why did you come here?' I said it is alright and went out [...] I was so sorry that the patient is regarded not as human but as an object." (Male patient)*

*Q13 "In its nature, TB is a disease with a character of being transmitted by inhaling contaminated air. But over there, I saw that when a patient's result is found to be TB positive, the behaviour exhibited by the professionals toward such patient is not good. Though I am not a patient, I was going here and there with patients. [...] There is even a patient's claim of being stigmatised by the professionals too. As she came closer to the doctor to present her result, the doctor told her not to approach and to stay away from his. Surely everybody taking care about his life, but this case is just a fear. Taking self care is good, but when we do it we should gently explain the patients about it, so that they don't feel any bad. A patient who came here for treatment must not go home with a psychology, would otherwise another problem will be created. This come to conclude that stigmatisation is practised by the educated section of the society. [...] In fact it would be better to use another mechanism that will prevent them from being contaminated. Otherwise the consequence of such act will bring about a complicated pressure on the patient. If an educated or knowledgeable patient is even told that he is found to be HIV positive, he appeases himself thinking that he must only care about himself by taking the anti HIV therapy and deal properly with the matter. But on the contrary, other TB patients feel disturbed and frustrated by seeing such ill actions. This is what I saw there." (Companion of female patient)*

*Q 14 "when you come to the doctors, the situation is more or less good. Though he does a good job, there is a doctor who, somehow, maltreats patients. The services they give are good, their knowledge is best of all, but a situation of treating patients [in an] unfriendly [way] is often observed. Not only this, sometimes ago, I had a sick child who was admitted here for treatment. The way they were saying things may even make sick a healthy person! If you take the case of an agonising child, imagine the family's level of anxiety. In relation to his profession, a doctor is expected to know about many things. A situation of making the family feel more worried is not acceptable. Similarly, the nurses are very good too. They are totally wrong. Their duty is to assist the doctor by translating what the doctor and the patient say, in case if they don't speak the same language. They are not entitled to serve as a doctor, but they act as if they are superior to the doctor. They don't treat people right. Though the service provided is very good, one might consider that there is no service at all because of the existence of such things. So it is better if there is a situation by which such ill disciplines are corrected." (Male companion of female patient)*

*Q 15 "When I received smear test result, I came to examination room. There one say: 'Go there' and the other says: 'Go there'. They mistreated me. I was seriously sick, that I cried. Lastly, they gave medicine." (Female participant)*

Q16 *“Some professionals do not want the patient to approach them. In the medical examination room, I approached one and she said: “Stay away!” She scared me. So, some do not show good hospitality.”* (Female participant)

Q17 *“There is discrimination around the card room. They give priority by knowing, kinship and well dressing. I saw one women who came last but served first. This is done by those who work in card room. There were many people who were seriously sick but she got priority.”* (Male participant)

### **Health information**

The majority of patients felt they could ask questions about their illness to staff<sup>Q2</sup>, or at least did not feel inhibited and most indicated they did not have unanswered questions. Some patients had a clear understanding of their diagnosis, including TB or pneumonia<sup>Q1</sup>, while others merely understood they did not have TB<sup>Q5</sup>. Some patients felt well-informed during their visit, having being told the importance of completing the diagnosis<sup>Q4</sup> before receiving a prescription<sup>Q2</sup>, receiving an explanation about their disease, advice on treatment adherence and the circumstances under which it was appropriate to return for further consultations<sup>Q1,3</sup>. Some previous attendees gave a clear account of the diagnostic process and were in some cases disconcerted by the change to a 2-day smear microscopy scheme and submission of on-the-spot sputum samples (as opposed to the consecutive morning specimens used several years earlier). A few would have liked to ask more information about HIV testing and the reason for repeated tests and visits. The absence of a clear diagnosis caused anxiety to some patients<sup>Q5,6</sup> and one was adamant that it was the patient’s right to know the disease they were suffering from<sup>Q5</sup>.

Examples of positive experiences of health information giving (Patients completing diagnosis, IDI):

Q1 *“I was found free from the TB. I was told that I was suffering from pneumonia and advised to takes the drug. I was also told to come back again in case if I don’t feel better after taking the drug.”* (Older male)

Q2 *“I asked her all the questions that come to my mind. I even asked her if she could prescribe to me some medicines ‘til I get my result on the next day. She gently replied to me that if she does so, my disease might be different from what she suspected and added that it was imperative to wait for the laboratory result. I was convinced and finally agreed to her idea.”* (Young male)

Q3 *“The doctor told me that they tried to find the disease in the sputum. She added that the disease is not only found in the sputum, but also either in the blood or in another organ. Then she explained me that such examination could not be done here because of the absence of the necessary*

equipment. However, she advised me to take that drug and added that in case it fails to be effective that I would be sent into another clinic for further examination. Therefore if no change is observed after taking the drug, then I will act as I am advised. [...] My worry was about the disease. When I told her that I have an abscess here, she answered that the drug may not be effective for that case, otherwise it will be effective. She just told me to come back after finishing the drug. I didn't get a satisfactory answer [regarding] the things I should do concerning the disease of my worry. Since the disease will not give me the relief for a single night, I was very worried how it would be possible for me to wait for the next 7 days [duration of treatment course]. [...] The doctors tried, but the disease was not found. The facts of advising me to come back again if I don't feel any better after taking the drug, or sending me to the referral hospital, are by themselves good answers for me. Since they have tried their best, I can't claim that they didn't try anything." (Young male)

Q4 "[...] my doctor gave me an unforgettable advice. It is good to explain clearly to the patients that the disease is dangerous and that it will cause a disastrous consequence on those who discontinue their examination." (Older male)

Examples of negative experiences of health information giving (Patients completing diagnosis, IDI):

Q5 "The result wasn't as I expected. I was told it was not TB. [...] when I went [to] the room in which I was examined with my result, there was another person. I had [a] card and she took the result with my name. She said that TB was not discovered. She asked me if I had taken medicine for TB before. I told her that I was given medicine for a cold. I did not take any other medicine. Now I did not know this medicine for what I was given. I gave the prescription to the pharmacist and received medicine. I did not know what my sickness is. I think this is one of the weaknesses. The [sickness] should [be] told to the patient. When I asked the cashier he said he did not know. He said the professionals know it. So I wanted to ask, but there was a queue at the examination room and I did not want to disturb them. I took my medicine. I was told by the druggist the time of taking [how often to take] the medicine. He told me to take these medicine[s and] to go to referral for X-ray if don't feel better. I think the patient should be told what their sickness is." (Young male)

Q6 "[...] patients should be given the information they need. Some patients do not know where to get information. [...] I suggest they should be given necessary information kindly about their sickness." (Young male)

## **Cost of attending diagnostic services**

### *Economic situation, direct patient costs and affordability*

Just over half of patients attending Awassa HC were working. Several had a regular income working as civil servants and skilled workers<sup>Q5</sup> (sports trainer, mechanic) and others had less regular or low income, working as traders<sup>Q8</sup>, guards<sup>Q9</sup>, waiters<sup>Q7</sup> or casual workers. Several were students<sup>Q4, 6, 13</sup>; others were unemployed or pensioners<sup>Q19</sup>. Younger patients, particularly students, often relied on their parents' income<sup>Q4, 6, 13</sup>; some were the sole earners in the family while others had other family members supporting the household<sup>Q7, 8</sup>. Although a few patients appeared to be comfortably off

and to have no difficulties in funding the cost of healthcare and treatment; many others reported selling assets<sup>Q18</sup>, exhausting savings<sup>Q18</sup>, putting the household under financial pressure<sup>Q4, 9, 11</sup> or seeking exemption from charges. Several patients mentioned moving around the country to find work<sup>Q11</sup>, sometimes leaving spouses or children behind<sup>Q2</sup>.

Direct patient costs described included clinic fees, transportation and non TB medication. Clinic fees in Awassa HC comprise a 5 birr (ETB) registration card valid for 6 months, after which TB diagnosis is free. Patients investigated for other diseases incur further charges. Patients did not mention being sent or charged for X-rays. Many patients appreciated the low registration charge<sup>Q19</sup> (and its long validity)<sup>Q12</sup>, comparing it with the private sector<sup>Q4, 5, 10, 12, 16</sup>. Most patients, therefore, found the cost of registration affordable, but the cost of transportation<sup>Q8, 15</sup> and non-TB medication more daunting<sup>Q13, 15</sup>. One suggested implementing a student discount<sup>Q13</sup>. Some patients carried exemption letters explaining they had no financial means (e.g. due to disability) and one participant's costs were covered by the employer. As expected, transport costs were higher for patients attending for several days. Some patients who paid for medication remarked the cost was considerably cheaper than in the private sector, while others felt it was equivalent, unaffordable and unjustified in a government institution<sup>Q9</sup>.

#### *Financial impact of attendance and illness*

Diagnostic attendance impacted on patients financially as they incurred opportunity costs, used savings, sold assets and put their families under financial pressure<sup>Q10</sup>, compounded by the fact that many patients had changed<sup>Q3</sup>, lost or temporarily halted their occupations<sup>Q2, 11</sup>, as a result of illness. Although a few reported no significant impact, the majority of patients indicated attendance for diagnosis meant lost revenues<sup>Q17</sup> as a result of shop closure<sup>Q15</sup>, lost trade, being unable to work in the fields or missing the most lucrative time for begging<sup>Q14</sup>. Several patients spoke of their illness leading to a reduced capacity to earn money, in some cases over a considerable time period. Many patients had also spent money on health advice and treatment before attending the Centre<sup>Q5, 11</sup>,

using savings and becoming indebted<sup>Q4</sup>. Patients spoke of going without food<sup>Q1,9</sup> and being assisted by friends and family. A patient reported spending all his money on the registration card and sleeping on the street.

Description of economic situation, cost of attendance and financial impact of attendance and illness (Patients completing diagnosis, IDI):

Q1 *"Whenever I get some money, I eat. Otherwise, I spend the night without eating. This is the way I live."* (Older male)

Q2 *"I got separated from my children for the sake of finding a job. [...] I came from [rural area]. But now I have no job. I was working around [other town] as a daily labourer in the construction of houses. But now I could not work anymore because I am sick."* (Older male)

Q3 *"Formerly I was a merchant. Now I am weak and I quit the work. I am earning a living by rent[ing] some rooms of my house. I am the father of 8 children. I don't have another job. [...] I have one child who has a job. I consider his having a job, as he is helping me. The rest have no jobs. They are not successful in their education and they are at home. [...] My wife has no job. She is a house wife."* (Older male)

Q4 *"my elder brother is educating me. [...] I am learning at [name] College of teacher education. [...] He supports me with financial support. [...] [Attendance] did not affect my financial position. In this summer I was treated in many places. I spent a lot of money. But compared to what I spent before, this one is very low. [...] Financially, my family was affected before my coming here. After my coming here I spent 35 birr and 50 cents. That means when I was treated repeatedly in other place, I spent more than 200 birr. It was at that time that I noticed my family was affected. Here I spent little money."* (Young male)

Q5 *"I was attending here before. I have family and am the father of one child. We are three including my wife living together. I am sport man. I am a club trainer. I was a football player before. [...] [Attendance did not affect my financial capacity]. You know why? I went to private clinic and I know about the private clinic. I spent a lot of money for this illness at private clinic. This includes the diagnosis up to medication. Here, they charges 5 birr for card. Blood test and sputum test are for free. So I did not spend much money."* (Young male)

Q6 *"I have two sisters and one brother. I have mother. I have a step-father. I live with them. [...] We live on our parent's salary. [...] All of them are students. No one has got a job."* (Young female)

Q7 *"I am the father of a child. I make a living by working as a waiter in a hotel. [...] My wife works. We support each other."* (Young male)

Q8 *"I have 7 children. Among them no one has a job. They are students. My husband is guard. I am trader. I trade little, little. Today came from [name of kebele] by taxi [and] paid 3 birr. [...] I spent 6 birr for transport double trip."* (Young female)

Q9 *"I divorced and have two children. [...] I raise them and support them. [...] I am a guard. [...] This is government's health centre. The government established it for the benefit of society. The amount of payment should be less than private [health centres]. The amount of some medicine is equal to private [health care]. Why this happens? That is the problem. [...] If a person is sick and in bed he*

uses half [his income] for his children's food and the rest for treatment. It is only if I am healthy that I can take care of my children. There is no other person who can help me." (Older male)

Q10 "the payment for the card is good. For example once I went to hospital. Card price is 20 birr. Here it is 5 birr. There is price difference. [...] [Attendance] affected my family. They give me money for diagnosis. The money they are supposed to use for another purpose, they spend for my diagnosis. They are affected on other hand." (Young male)

Q11 "I came here [Awassa] for work. [...] I don't have brother and sister here. I have friend. I live with him. My family is in the rural area. I have two brothers and three sisters in my place. All of them are my elders. [...] My mother died when I was young. [...] in 2001 E.C. my father died. I came here because of this. I do my private work. [...] The illness started a long time ago. I went to a private clinic and got some medicines. But there was no change. I make a living hand to mouth so I could not afford the expense. If my friends did not help me with food and opinion [advice], it would be difficult for me. [...] I spent a lot of money for the time I got sick. The expense was difficult for me. [...] Before I got sick, I was working a little. After I got sick I could not work and stopped it. My friends are supporting with food." (Young male)

Q12 "I am raising my child [alone]. I am government employee. [...] The payment [...] considers the living standard of the society. For example you spend 5 birr for card. You can use this card for 6 months. Payment for laboratory is less. In other places for the card they charge 20 birr. After 10 days if you go again, you will pay another 20 birr. They charge high price for laboratory. After spending that much you may not get solution." (Female)

Q13 "Many people say that the payment in a government clinic is cheap, but I paid 31 birr [for medication], it may also be more because I still don't know the price of the drug. I think that a special discount should be made practical for students and poor people. Look! I paid 30 birr for this pill. Besides this I am a student - I don't have my own revenue. I am only depending on my family. So; I think that the cost is beyond the capacity of people." (Young male)

Q14 "I was given an appointment to come back at 3:00 pm. I have to accept it because it is a question of health, even though 3:00 pm is crucial time to me for getting my daily bread [begging]. But nothing is more important than my health. In fact, I would have been happier if I was able to get my result on the first morning. If it did not happen to be so, I am obliged to wait for it since it is a manmade result. It is an obligation to accept the appointment given by the professional." (Young male)

Q15 [My financial situation] was seriously affected. The time I spent here on Friday would have been worth of not less than 50 birr. Even at this time my shops remains closed. In addition to this, I spent some money for the drugs and for taxi. I was pretty much affected." (Young male)

Q16 [...] since the treatment payment of this health centre is less, many people are coming here". (Young female)

Q17 "It affects financial position. I work for an individual. I earn money only when I work - on contract agreement basis. Health is better than everything. If I am able to live I can work. I gave most of time for treatment and it affected me." (Young male)

Q18 "I am a worker of coffee enterprise. I work loading and unloading coffee. My income is 800 - 1000 every two weeks. Our income is varies. [...] I am very sick. Starting from May I am attending treatment. I withdraw my money. I had bank around 3000 birr and spent it for treatment. Now I got treatment by selling tape recorder. [...] I support three family [members] including my wife. [...]

*I had treatment in different places. They give medicine for 7 days. When the illness gets worse, I stop the medicine and go to another place. It is in this situation that it made me to be in bed up to the last time. In this case, it affected my financial capacity.” (Young male)*

*Q19 “I am now retired and my revenue is based on my pension. [...] It has not affected me at all. The money I spent here was below my expectation. My worry was about being a TB patient and staying continuously under medication for a long time. Because I have completed everything in a short time, I was not financially affected. Disease negatively affects your means of income.” (Older male)*

### **Overcharging, underhand payments and preferential treatment**

In contrast to results presented in chapter 6, there was only one description of financial impropriety by staff. This was a patient who noticed the cashier withheld change from patients<sup>Q1</sup>. Otherwise, one patient believed staff allowed patients to jump the queue<sup>Q2</sup>. However, this may have been a misinterpretation, since patients attend for different health conditions and follow different examination routines.

*Q1 “[...] after I paid some money to the cashier. I asked him to get my change for me. But in fact, I was sure that he should owe me some change. Their behaviour changes according to the personality of the individuals.” (Young male)*

*Q2 “I did not understand how it happened, but I have observed that a patient who arrived here after me has got the chance of being admitted to the doctor before me. In addition to this, I knew that a patient who came after all of us has completed his examination before us. These situations were unpleasant for me.” (Young male)*

### **Enablers and barriers for attending and completing diagnosis**

#### *Financial, economic and work factors*

In contrast to the results described for Yemen, none of the patients were referred for further private tests and medications or described X-ray charges. Attendance was variously facilitated by financial support from an employer<sup>Q4, 5</sup>, exemption from diagnostic and treatment charges<sup>Q1, 3</sup>, a handout from a passerby<sup>Q3</sup>, reduced outgoings due to a short diagnostic process<sup>Q1</sup> and living in proximity to the Health Centre.

Examples of facilitating factors (Patients completing diagnosis, IDI):

*Q1 “When I asked them to help me because I had no money, they gave me the drug. [...] [The process of completing the examination] was smooth because I hadn’t to pay much money. I was not given an appointment for the week after. As soon as I came here, I was examined and given the*

necessary drug. Had I gone to private clinics, I would have paid a lot of money and given a lot of appointment. I might also be asked to pay another money. Such events would have forced me to give up and led me to death. These are the reasons that made me say that it was simple.” (Older male)

Q2 “[Attendance at DP] did not affect my financial position. In this summer I was treated in many places. I spent a lot of money. But compared to what I spent before, this one is very low. [...] Financially, my family was affected before my coming here. After my coming here I spent 35 birr and 50 cents. That means when I was treated repeatedly in other place, I spent more than 200 birr. It was at that time that I noticed my family was affected. Here I spent little money.” (Young male)

Q3 “[...] because I am blind I live by begging some money from the passersby on the street. I was able to come here for treatment owing to a recommendation letter that I brought from the national Association for the Blinds regional branch office which is established here. The letter allows me to be exempt from any payment. Even in the case of a severe condition, the cost of my treatment at a higher level will be covered by the government. I also got my drugs now free from any charges. Such service is only possible if our country is peaceful. [...] when I was coming now, a lady considered my miserable condition and paid for my taxi. [...] concerning the payment, after paying 5 birr one is entitled to get treated for 6 months. Whereas, in private clinics 20 birr is paid to see the doctor and is also followed by some additional expenses. So it is really disastrous. If you can afford it you are obliged to pay for the laboratory and for other requested tests. All in all you might be required to pay a minimum sum between 100 and 200 birr. Without the subsidy of the government this health station would not be able to operate by collecting 5 birr only. I don’t consider this 5 birr as being costly. So it is good to have a 6 months medical service, that can also be renewed, with the cost of 5 birr.” (Young male)

Q4 “I was sent by my organisation. It pays the medical expenses for me. They are the ones who told me to come to this health centre. First they told me to go to referral hospital. I said I would not go. I don’t know much about the hospital. There was no one to go with me so I came to [name] Health Centre. I can’t go to referral by bicycle for I am sick. I said I could not afford to go by taxi, so they sent me to health centre when I asked them, as I wanted. [...] It did not affect my financial capacity. I got two days permission from my organisation. I didn’t pay much. It is good. However much the expense may be, my organisation covers it.” (Young male)

Q5 “It was easy. You know why? In the first place I have permission from my working place. To work I have to be healthy. If you are healthy you can fulfil your responsibilities. I informed my boss that the treatment takes three days. So, nothing can affect my works.” (Older male)

Attendance was impeded by a lack of financial means<sup>Q6</sup>, opportunity costs<sup>Q8</sup> and disruption of daily activities<sup>Q7</sup>. One patient felt he had to attend the Health Centre as he could not afford to go to the private sector, which he perceived provided faster and better services.

Examples of inhibiting factors (Patients completing diagnosis, IDI):

Q6 “Yesterday I got only 5 birr in my hand so I sold my sweater for 6 birr and paid for the card. I spent the night on the street. The next morning I got 1 birr by begging.” (Older male)

Q7 “I am a university student and thus I was very busy. The reason which prevented me from coming earlier was my unwillingness to disrupt my study. I was even thinking that it would be better to wait patiently until I take the final exam. But the worry about the disease brought me here [...]. Soon

*after I came here, I was very scared when I was told that I should give sputum at that time and come back the next morning [2 day diagnostic process]. I had even decided not to come back again. [...] let alone at the level of a university, even in high school being absent from any class is very bad. There is no free time at a university. If a student is absent just for one day, he will miss a lot of knowledge. [...] a one day class is very important to me especially during the exam time. Nobody is allowed to ask for permission. If you happen to miss any exam then nothing could be done for you. The lecture that I missed by yesterday and today can only compensate by sharing my study time to copying the notes. In this way I will try to cope alongside the other students. Therefore, I was pretty much affected.” (Younger male)*

*Q8 [...] the worker at the laboratory who made me wait for such a long time has slightly upset me. Instead of going back and do my business at the shop, I wasted my time just for nothing. One has to remember that at this very time even a single hour is enormously precious. It is a loss when one’s shop is left closed.” (Young male)*

*Q9 “I know there is day off for the holy day. I would be happy if I completed on the same day. I have expense for taxi. But what can be done if it is must [unavoidable].” (Young male)*

### *Physical factors*

Residing near the health centre facilitated attendance physically and financially. Several patients found it difficult to complete diagnosis due to their ill-health<sup>Q1-3</sup>, which resulted in being too unwell to return for appointments, experiencing pain while waiting for medication<sup>Q1, 2</sup> and physical deterioration. One patient slept on the street as he lived far away, another was scared of dying overnight and another indicated his condition worsened while waiting a week for diagnosis.

Examples of physical constraints (Patients completing diagnosis, IDI):

*Q1 “I found [the medical examination] hard because(,) since [I] had a severe internal pain, I felt bad when I was given an appointment for the next day. I would have been glad if I was given some drugs that could alleviate my pain. The high level of my pain made it hard to [for] me.” (Young male)*

*Q2 “Yesterday I was seriously sick. It was really difficult. The diagnosis was not complete. I was feeling pain inside.” (Young male)*

*Q3 “I started feeling sick 6 days ago. I could hardly arrive here.” (Older male)*

### *Psychological and social factors*

Several patients expressed it was not very difficult to complete the diagnosis. Knowing in advance, or on arrival, the duration of the diagnostic process seemed to prepare patients psychologically and facilitated completion. Patients were concerned for their health<sup>Q3, 5</sup>, were fearful of dying<sup>Q4</sup> and

were motivated to recover to regain an income and care for their family. Some patients understood the importance of completing the process so that health professionals could understand their case<sup>Q6</sup>. Some patients received psychological support, encouragement and advice from acquaintances<sup>Q1</sup>, patients<sup>Q8</sup>, health professionals and Health Centre staff. For example, a few patients felt encouraged to complete the diagnosis due to the fair treatment and healthcare received. Two patients considering dropping out were persuaded to continue by family members<sup>Q2</sup>, one of whom explained that the process is common to all patients and that he was not being treated differently<sup>Q7</sup>.

Examples of psychological and social enablers (Patients completing diagnosis):

Q1 *"There is a person [...]. The one I told you that I met her on the road. I rented a house from her and lived for one year with her. She advised me to go straight to clinic to be diagnosed. She encouraged me to go[. Even] even if I don't [go she] promised to show me the way. I got idea [moral] support from her. [...] Even they [people around me] encouraged me to come here. They told me to go to the health centre rather than going to the private one. When I met some people I knew, they said: 'Did feel [Are you feeling] better?', so I told them that I went to health centre. They said that it was good. They asked me to tell them the result after the treatment."* (Young male)

Q2 *"Even today I was to quit or not come. [...] The reason is that I quit my work to come here. [...] My wife pushed me to come. "* (Young male)

Q3 *"I was seriously sick [...]. Because of this I thought it would be tuberculosis and I was concerned."* (Young male)

Q4 *"I thought that if my condition becomes worse, then the worst will happen."* (Young male)

Q5 *"Let whatever happen but the top priority goes to my health. Once I started my medical examination I have to go through with it up to the end. Therefore, I will never give it up or discontinue it. One might give up other things, but the question related to health must be dealt seriously."* (Young male)

Q6 *"In order to get fully healthy, I have to undergo the entire process of the examination and get aware of my case. That's why I hurried to come here."* (Older female)

Q7 *"[...] I consulted my brother. When I asked him, he assured me that there won't be any problem and advised me to go. He urged me that I should complete the examination and not to give it up by my own decision. He kept on advising me that the process of the examination is common to all patients."* (Young male)

Q8 *"When I asked my result, they told me to go to the room where I had [been] examined. There are some good people. They treated me very well. There was a woman in my village who knows everything about the health centre [who] helped me."* (Young male)

Other patients indicated that anxiety about their health<sup>Q9, 10</sup> and the implications of a TB diagnosis<sup>Q12</sup>, and fear of dying overnight<sup>Q14</sup> made attendance psychologically difficult. A few patients felt pressurised by others to seek private healthcare<sup>Q11, 13</sup>.

Examples of psychological and social barriers (Patients completing diagnosis):

Q9 *"I found it a bit difficult. Suddenly I thought I might have tuberculosis."* (Young female)

Q10 *"I worried about my result - what it would be."* (Young male waiting over the weekend)

Q11 *"So many people were asking me about the reason why I shouldn't go to private clinics. When I tell them that I have an appointment at this clinic, they raised the same idea. They even went as far as saying that I was against their idea because I didn't want to spend much money, but that was not true. I argued with them that this is a government institution established to take care of my health. And I succeeded in being healthy. So I am happy. [...] in my opinion government clinic is better. (...) So because I know that fact I did not accept the idea of my advisors."* (Older female)

Q12 *"I found it hard. This was because I was very afraid of being found TB positive and worried much about the consequences [for] being able to run my business."* (Young male)

Q13 *"It was really difficult. The diagnosis was not complete. [...] [I went] to my village and told them. They told to me to go private clinic for [it] is better than that of the government. But I did know a lot. People in my village suggested that the expense of the health centre is discount, but the service of the private one is better."* (Young male)

Q14 *"I worried very much to get my result. When I was told that the result would be the next day, I thought I would die on the night before result, because my illness bothered me. [...] The examination process was scary to me."* (Young male)

#### *Gender related and cultural factors*

Women participating in the IDIs did not report specific difficulties to attend or complete diagnosis; however the FGDs revealed many barriers for women. An all-female FGD was particularly informative. Male and female participants agreed that access to healthcare for rural women was more difficult than for men<sup>Q2, 3</sup> and agreed that the health of women in rural areas is given less priority<sup>Q1, 4-5</sup>. Women in rural areas were perceived to have a lower social status<sup>Q5</sup> and to present to health services when they are seriously ill; while men present early on<sup>Q1</sup>. The problem was felt to stem from lack of emancipation, in particular financial autonomy<sup>Q1, 9-10</sup>. Female participants described rural women's dependence on their husbands<sup>Q1, 10</sup>. Women found difficulty leaving

household tasks and children, which are regarded as their responsibility<sup>Q2, 10, 16-17</sup>. Within a traditional cultural role, women must first inform their husbands or senior males in the household of their illness and ask permission to seek healthcare<sup>Q1, 10</sup>. Some females suggested that rural and urban women might hide their illness until their husband noticed their illness and sought healthcare<sup>Q8</sup>. Some said men also hid their illness, presenting late to health services and not informing their spouses<sup>Q8</sup>. Town and city dwellers were said to be more educated<sup>Q5</sup>, with women working and having more financial independence. In an urban context, couples discuss the illness and seek help together<sup>Q5</sup>. Some women said women in urban areas had equal access to healthcare<sup>Q1, 10-12</sup>, as urban society had been modernised and gender roles were more egalitarian. Some men suggested urban women were victims of their own negligence by failing to seek healthcare<sup>Q3</sup> and that in some families their health was given priority over men's<sup>Q3</sup>. Other men did not distinguish rural from urban culture, maintaining that there was no differential access to healthcare by sex<sup>Q6</sup> and that the key was having sufficient financial means<sup>Q13</sup>. Although women are traditionally accompanied by a male, who acts as a spokesperson and protects and supports them, this convention was perceived to be changing, as some women were attending alone<sup>Q7</sup>. Women and some men indicated that it is more difficult for women to attend and adhere to treatment, since they have so many responsibilities at home.

Examples of enablers and barriers relating to gender (Patients completing diagnosis, FGD):

Q1 *"In countryside they are not equal. I worked in [the name of] rural areas. There is a big problem there. I was working for [the] health centre. What I observed there is when women are taken ill they come to health centre late with someone's support. They are brought after it has been serious. They are brought by donkey cart. Males come on time before it gets worse not like female. So it is determined by development because in urban areas all are equal. In fact, there is a problem around the rural areas. [...] The problem is economic problem. A woman has no money. She can't do things by herself. She is under a male. She needs permission from her husband. Without her husband's permission a wife cannot go to receive treatment. We have raised this situation many times. When the mother of his children is sick rather than bringing on time he brings her after she became seriously sick. This may be because of lack of knowledge or cultural influence. When he himself feels sick, he goes to seek for treatment. The money is in his hand. He enjoys himself. He has full right. Still around the countryside this is not solved."* (Female participant)

Q2 *“Woman’s problem is a lot. For example, even if she is sick the responsibility of taking care of children falls on her, so she prepares breakfast or lunch and she will be late [to health services]. She cooks breakfast and cleans the house, she takes children to school. The husband simply looks at her. So, in rural area there is a lot of problem on a woman.”* (Female participant)

Q3 *“[...] we look this idea by dividing into two. These are women in the urban and rural areas. In the rural area women have less chance to go to health centre. In urban area the chance for both man and women is equal. Even the husband gives priority for his wife I think. However, women got hurt by their own negligence I assume that they are not as quick as men. [...] The reason is traditional/cultural situation influences the women a women is not quick to go far for sick care. She informs but a husband goes for treatment without telling his wife.”* (Male participant)

Q4 *“I support what he has just said. In the rural area women are not given attention. But in urban area it is good.”* (Female participant)

Q5 *“[...] rural [...] women are dependent of their husband. They have no their own things, leave alone to go for examination there is nothing to be eaten. Good food is given to husband. Everything is under the control of the husband; so she cannot afford to treatment or go to health institution. If she gets sick, she has no acceptance. She is not given place. It is not exaggerating the husband does what he wants and eats food he wants. He also eats good food at home. The wife eats the leftovers. This is clear problem. She doesn’t go to health institution rather she stays at home until she dies. This is selfishness. If she is infected with TB he will also be infected. [...] In the urban area most people are educated and have work, so both can equally get health service. Both think of each other, for example three of us sick and came together for medical examination.”* (Female participant)

Q6 *“I don’t see difference between men and women. [...] I think all are equal nowadays.”* (Male participant, urban resident)

Q7 *“until the present time women were culturally and economically dependent on men. Liberating women to act independently is still being given some concerns and things are getting better than before. Previously were thought to seek the support of men particularly during their life in marriage. Nevertheless, if women come alone or without the assistance of someone else they don’t have the chance to get as equal service as man. Therefore, they are usually accompanied by someone. [...] these 2 days, I saw that women are getting a good service here. [They] come here alone or accompanied. If you consider the case of my mother, I accompanied here because she can’t manage things by her own. This is due to her previous awareness and lack of experience of knowing the entrance of and the exit of each section. This time there is a good psychological treatment for both men and women who want to act by themselves.”* (Male companion, urban resident, Bushullo HC)

Q8 *“I experienced [witnessed the experience of] two people. Women fear to tell their husbands with regards to their problem. A woman who fears to tell her husband tells to another woman – her friend. She does that when the problem became worse. There is no discussion. Soon she got sick. She says that she is always sick. She complains always. Her husband asks her ‘What happened to you?’ She says nothing. She hides from her husband and tells the outsiders, which has no value. If she had told him from the beginning, he would have sought solution to the problem. He will not be quiet and see her cooking being sick. He did not know her problem, but he knew after she was taken to health institution at last. The husband said that she hid the problem from him. The doctor advised her that there is no-one closer to her more than her husband so that she should tell her husband all her problem. [...] The other one is that the man or the husband who does not tell his wife the problem he faces. There was a married woman who went to health institution for treatment. She saw her husband there when he had treatment. ‘Oh, what is this man doing here in the place*

where women receive treatment?' she said to herself. I came here for ovary problem [...] While we were talking about him, he came. He entered all the treatment room she entered. [...] So hiding itself is a disease. Women face a lot of problems." (Female participant)

Examples of enablers and barriers relating to gender (Patients registered for treatment, IDI)

Q9 "I think the opportunity for men is higher [...] in financial position. Most of the time most married women may not have money. They receive the treatment with the support of their husbands. It is a man who does a job. A woman stays at home. A man has wide chance of being examined in case he is sick. But when a woman is sick it is the man who takes her to health centre for treatment. So I think the position of a man is better than that of woman's." (Male participant)

Q10 "In rural areas there is a woman who stays at home and waits for her husband. He might be a merchant around urban area. In case he gets sick, he receives treatment easily and come home. We can be affected while we wait for our husband. Most of us do not have anything in our hands, because it is the man works and brings money. In rural areas most of the time women are affected because they have no means of income and they look after their children. In urban areas man and woman are equal." (Female participant)

Q11 "Whether a man or a woman, both are equal when they get sick. I think they both can go to the health centre to get treatment." (Urban female participant)

Q12 "When it comes to health there is no male or female." (Urban female participant)

Q13 "Now here there no difference between man and woman in the house because of sex. Disease is the same for man or woman but to take care of the patient, the status of the family determines." (Urban male participant)

Q14 "[...] a man or a woman is not different. Also with being sick, there is no difference. In Ethiopia, a person who is sick, even a child, has respect culturally." (Participant)

Q15 "Women cannot get treatment as they want. Sometimes they shoulder the burden of their family." (Male participant)

Q16 "Women are late for treatment because they take care of their children and cook breakfast for their family man has no problem. The burden is on the women. He can leave everything and go in the morning. So when we compare the problem of the man with the women's problem. Women's is difficult. After arriving at the health centre, there is no problem." (Female participant)

Q17 "There is a girl where I live. Most of the time she does the entire house work. There is disagreement among the household sometimes, so that the workload falls on her. She was coughing while she was working. [...] There is such kind's problem in the family who cannot understand the problem by working like this she will not recover from her illness and by taking medicine she will not feel better. I think the work load has this kind of impact. She cannot feel better by working while she is feeling sick repeatedly." (Urban male participant)

*Returning for a second day of diagnosis and possible reasons for abandoning the diagnosis*

A few patients found it reasonable to return for a second day or to wait over the weekend and were respectful of the time professionals needed to process test results<sup>Q1-4</sup>. Many patients however

found it difficult to return<sup>Q11</sup> and some considered dropping out<sup>Q7</sup>. Some indicated they were suffering with the illness<sup>Q6-7, 12</sup>; others had expected to complete the diagnosis in one day<sup>Q9</sup> and did not understand the reason for being asked to return<sup>Q8, 12</sup>. Others considered seeking private healthcare<sup>Q10</sup> or were concerned about lost business. One patient who waited over the weekend was concerned about the implications of delay for sputum quality and continuity of care. Two patients believed they could access a private weekend service. Patients offered explanations as to why others might not return. These included being put off by the negative attitude and poor manner of staff.

Participants in FGDs confirmed that many patients consider dropping out due to the attitude of administrative, laboratory and clinical staff<sup>Q13, 16, 18</sup>. Further barriers included a failure to realise the seriousness of their illness<sup>Q15, 19</sup> and a culture of treating illness through traditional healthcare<sup>Q15</sup>, the diagnosis requiring repeated visits<sup>Q14</sup> and a shortage of money<sup>Q15</sup> or support<sup>Q20</sup>. Patients dropping out often turned to over-the-counter medicines, private healthcare<sup>Q14, 16</sup> or traditional remedies. Fear of the disease<sup>Q18</sup> and of the attendant social consequences was also proffered as a reason for abandoning the process<sup>Q17</sup>.

Examples of enablers for returning for a second day of diagnosis (Patients completing diagnosis, IDI):

Q1 *"Is there a seed that is sown and harvested the same day? Therefore waiting was obligatory."* (Older male)

Q2 *"They have explained to me in advance that it will take me three days that is [from Friday] till Monday. With [this] in my mind, why should I be annoyed?"* (Older female)

Q3 *"I felt nothing because I was formerly aware that the process goes like this. Previously it was even reported to 3 days after. And when I came here some people told me that it would be so. On the first day I was requested to give 2 samples of sputum. The next day I gave the third one. That is it. I am so happy to have completed my examination within a short period."* (Older male)

Q4 *"I was happy because I want to know my result. [...] I was very eager to have my sputum to be tested, so I was very happy."* (Young male)

Examples of barriers for returning for a second day and (potential) reasons for abandoning diagnosis of diagnosis (Patients completing diagnosis, IDI):

Q5 *"[...] if they are off on Sunday, [...] they should have worked Saturday."* (Young male)

Q6 *"I was disappointed as I come from [a] distant place and was feeling pain."* (Young female)

Q7 *"I [was] annoyed when I was told to come on Monday for sputum test. In my heart I was annoyed. I said how I can stay up to Monday being sick like this. [...] I will die. I thought to go to another place. My illness is getting worse. I am feeling pain in my chest and back. I hardly breathe."* (Young female)

Q8 *"I was very disappointed. 'I have to get [the result] today. Why you tell me to come tomorrow?' I said to her. I did not know that there was no one to take the sputum, because she did not tell me. She [just told me] to come tomorrow only. [At least she could have told me] to come tomorrow, because there was no one to take sputum. I said: 'Okay' and asked her when to come. She said: 'Come tomorrow. They have got meeting.' I was annoyed because I had not that experience. I had sputum test experience twice or three times before. It was not like this one."* (Older male)

Q9 *"I was annoyed. I was thinking to get the result on the same day on Friday."* (Young male)

Q10 *"I even thought of deciding about not to come back here again and go to a private clinic with my brother. I changed my idea because my brother explained to me that even the private clinics are not on duty on weekends and advised me to come and see the situation here."* (Young male)

Q11 *"When people are sick they get very worried, such as me. It is better to treat them within a short time. It may be very hard for them to come here for 2 consecutive days. If you take my case I have always a severe cough during the nights. It was because of this frequent bad condition that I wanted to finish soon and got scared on the news of coming back for the next day. Therefore, it is good to improve this process. I wonder what could happen to patients who may come here being more worried than me. Therefore, time must be given due consideration."* (Young male)

Q12 *"I was annoyed in the next morning. I come at 2 o'clock [8 a.m. European time] in the morning to get medicine and come back home, but I was told to take the result of the laboratory at 9 o'clock [3 p.m.]. It is again 9 o'clock in the next day. I didn't get pain killer. I was angry and annoyed."* (Young male)

Barriers for returning for a second day (Patients completing diagnosis, FGD):

Q13 *"the man who checks blood pressure before the examination room, shows some kind of ill-treatment. I said: 'Please I am sick and I came here for treatment. Don't maltreat me'. I was to quit the treatment to go back home. (Male participant)*

Q14 *"I was commuting most of the time from home to [Health Centre]. I also did not complete the diagnosis. Most of the time I was given syrup [...]. I used it and there was no effect. So when I came again they prescribed sputum test. Because of this I gave sputum once and quit it as a result of getting bored. When a person loses hope on examination, he can quit diagnostic process. In this case the first day I gave sputum. They told me to come the next day. I said: 'Okay' and went to private clinic. [...]" (Female participant, defaulted from diagnosis)*

Q15 Participant 1: *"Some people may face shortage of money for commuting. Another [reason] is negligence and it may be lack of attention to the disease."* (Male)

Participant 2: *"Yes. There are many people who start the sputum test and medicine, [but] stop in the middle. This is the main obstacle as my sister said. Lack of money is one; the second thing is the negligence of people. They feel as if the disease goes away by itself. Especially there are many local advisors in the villages. They say: 'Don't go to health centre for this. This can be cured with this and*

*that. So and so who was sick last time got cured with this.’ This kind of advice encourages the people to quit the examination and to turn [...] to traditional treatment. When a patient comes back home, there are many visitors. All of them become doctors! One says something and the other says another thing else. There are many who say: ‘Don’t spend your money for nothing’. In this case, many accept their advice and quit the diagnostic process. This will eventually become problematic and risk for their health. Another point: their [the villagers’] low awareness confuses the patients.” (Female)*

*Q16 “There is a situation of mistreating. When you go for treatment one says: ‘Here’ and the other says: ‘There’. Lastly I told her that I was sent to come here. I was disturbed when I heard that it was TB diagnosis. [...] Lastly when she took the paper and read the paper was written to referral hospital. Later the other [said it] is not. He made me diagnosed here. When I gave sputum in the morning at 9 o’clock and I came for the result, they prescribed medicine for me for 10 days. If you don’t feel better after 10 days, come back again. I took the medicine for 10 days but I didn’t feel better. Even I could not stay for 10 days; I come back on the 7th day. I obtained card and went again to give it to the girl [...]. I heard the girl say card does not come back to her. She refused to take my card, but she is taking others’ card in. I was seriously sick and it was making me cough. My husband was saying he was to take me to another place. I am telling him I should complete it where I started. She was talking with someone holding my card. They could not break [interrupt] the talk. I said to her that I was feeling pain. ‘Is my card with the doctor?’ She said: ‘Yes’ and went out, then I myself went then saw it. Even if we put the card on top of others, there was nobody to call patients’ name. We waited a lot and finally my husband took me to another private clinic. Generally when you see it is not good. Most of them mistreat patients. There are a lot of these kind of things. This kind of thing should be addressed [...]. They should take care of the patients. Otherwise the patients will be affected psychologically.” (Female)*

*Q17 “It is he may be afraid if the sickness is known to be TB, it will be noticed by someone. So it is because of fear.” (Female)*

*Q18 “I think most people fear TB, if he give sputum and the illness discovered. Another one is the way the profession treat the patients. If they mistreat them, they will not come back the next day.” (Female)*

*Q19 “Giving no attention to the illness. If coughing is not serious they consider it as a cold. (Female)*

*Q20 “It may be lack of capability. If my son did not support me I would be in trouble. It may be lack of support.” (Female)*

### *Sources of support*

Many patients received support from family members, friends or neighbours. One patient felt well supported by the Health Centre, who provided free prescriptions and another by his employer, who covered the cost of attendance. Support included encouragement to attend<sup>Q2-4</sup>, being accompanied to the Centre<sup>Q5</sup>, physical care<sup>Q1</sup> and the provision of food<sup>Q5</sup>. TB patients registering for treatment reported receiving the same assistance from friends, relatives and employers<sup>Q6-8</sup>.

Examples of support (Patients completing diagnosis, IDI):

Q1 *"The main support is [my] wife. She has no income; however she is the highest source of my support. When I feel pain she sits beside me and comfort me (...). [...] The workers' support in taking care of me helped me to complete [the diagnosis]. It is good because the workers are working from their heart."* (Young male)

Q2 *She said, 'The way you [are] coughing is not good' [...] I came here because she told me it would change into TB."* (Older male)

Q3 *"[My mother] can't afford [to support me financially]. The cost of living is very high with what she pays house rent. I support myself with what I work and earn. [...] My mother supported me with advice and suggestion."* (Young female)

Q4 *"[...] my brother. He is health professional in another place. He told me to come here for treatment. He said that he would be with me to assist me. There are also my other family."* (Young male)

Q5 *"[...] my friend who escorted me when I came here. I was seriously sick when I came here. When I asked him to go with me, he said: 'Okay' [...]. [...] I eat with my friends. I had no problem."* (Young male)

Examples of support (TB patients registering for treatment, IDI):

Q6 *"I told a female teacher I was sick. She told me to go to the health centre right away by giving some money. [...] her husband is the health professional. They assist me with every necessary thing to attend the treatment. They tell me to take the medicine properly. They say to me 'If you need money we will help you'. [...] [We have] work relationship. They take me to different places to work for them. Because of this we see each other as a relative. [...] they visit me every day. They ask me whether I went to the health centre to get medicine or not. They tell me to sit down to eat what they have in their house. When I leave they give me money. It means they support me."* (Older male)

Q7 *"I consider as pressure that they ask me what I need and gave me transportation fee for Bajaj taxi. They worry about me and [I] understand that they are affected. My sister gives me some money for milk and transportation. She is making her living by cooking for others. She pays for house rent. More than these all them worries about me. [...] I rely on them asking them to buy me something. [...] if I were not sick I wouldn't need any help from anyone. I had my own salary, but now I don't have. [My sister] was encouraging me that she had lung problem and she got better. She tells me if I carefully follow, I would recover from my illness. She says I should complete my treatment."* (Male)

Q8 *"my boss himself told me to get medical treatment. They facilitated by giving me advice that it is getting worse. I also convinced myself that I should have treatment. [...] my boss helped me [...] until I got treatment. [...] He helped me with some money for Bajaj taxi, for stool test & for all examination tests. He covered the expense. [...]. When I went [name] health centre for the first time, I went with my boss. He was my co-signer to receive treatment. [...] when I am present he takes day off & when he is present I take day off. When I come here, he covers my place. [...] if don't arrive on time, he covers my place in the work. [...]"* (Female)

Several patients completed the diagnostic process alone or indicated nobody had supported them.

Some were uncomplaining and independent-minded<sup>Q12</sup>, or did not want to worry family

members<sup>Q11</sup>. Others lacked support in certain areas; such as financial assistance<sup>Q10</sup>, or the moral support of being accompanied to the Health Centre<sup>Q9</sup>.

Examples of lack of support (Patients completing diagnosis, IDI):

Q9 *"No one [supported me]. My husband is a guard and comes in the evening. No one came here to assist me. Only God assists me."* (Young female)

Q10 *"I need [financial support]. Because I am a student."* (Young male)

Q11 *"No one helped me. I did it by myself. I get sick very often so I didn't want to bother my family. [...] I did not tell anyone that I was sick and I was at home the whole week, but I didn't tell them."* (Female)

Q12 *"Here I have no relatives who help me. I support myself by working and living alone. So I did not want special support."* (Young male)

### **Patient understanding and report of diagnosis and diagnostic process**

Many patients gave a clear account of the routine for submitting and testing sputum<sup>Q2</sup>, including the need to produce quality sputum<sup>Q3</sup>. A few were confused and irritated by the need to submit several samples and to make several visits<sup>Q7</sup>. Many were told they did not have TB<sup>Q2</sup>, but only a few indicated they had been given an alternative diagnosis<sup>Q1</sup>. Some patients diagnosed with TB were relieved that their illness had been identified and could be treated. For the same reason, some patients without TB were disappointed<sup>Q5</sup>, as they continued to worry about their illness, although several were relieved<sup>Q6</sup>. Some of the latter understood when to return to the Centre if their symptoms did not improve<sup>Q1</sup>.

Illustrations of patient understanding and report of diagnosis and diagnostic process (Patients completing diagnosis, IDI):

Q1 *"I was found free from TB. I was told that I was suffering from pneumonia and advised to take the drug. I was also told to come again, [...] if I don't feel better after taking the drug."* (Older female)

Q2 *"Next we went in to the examination room [...]. I was asked how I was feeling and I told them. I was told to go [...] for sputum test. There I gave my sputum. It was Friday and I was told to bring another sputum on Monday. Today I came with it and I was given appointment. When I came according to my appointment I received the result. The result wasn't as I expected. I was told it was not TB. [...] Sputum was taken in three days but now it is given in two days. There is one day difference. The time for receiving the result is short. If the sputum given after breakfast has no problem, it is good for me. Though the disease is not found, there is a way of giving medicine for those who have the illness"* (Young male)

Q3 *"I started on Friday. On Friday I could not have sputum, so I was told to bring the next morning. The morning I had no sputum, so I was told to bring on Monday. On Tuesday I gave my sputum. They told me to bring another one spitting it before having breakfast. Then I gave them and they told me to come at 9 o'clock in the afternoon."* (Young female)

Q4 *"When I was giving sputum, it was late (lunch time). They cannot stay here for me, so they should give an appointment. The sputum was waterish. The morning sputum is thick. That is why I brought the morning sputum. I was given an appointment for 3 o'clock in the afternoon. I also took medicine I did not lack anything. [...] I just came and was given card. Soon I saw the doctor and she prescribed laboratory test for me. [...] I gave sputum and she was not happy with it. She told me to bring the morning thick sputum. I agreed and took it in the morning. [...] I have no complaint."* (Older male)

Q5 *"I was little disappointed when I was told that I did not have TB. I was given another medicine. I was told to go to hospital after I finish the tablets they gave me."* (Young male)

Q6 *"I was afraid of being TB positive, but thank to God it was a happy ending."* (Older female)

Illustrations of lack of understanding of the smear microscopy process (Patients completing diagnosis, IDI):

Q7 *"After the card room, what I faced at the examination room is that the nurse was good. She sent me to the laboratory before reaching the cash room. I worried very much. While I was sick and worrying, the cashier came and I paid [and] was sent to the laboratory. I was very sick. The laboratory technician told me to come at 9 o'clock. When I came 9 o'clock, she told to come the next morning. From 10 o'clock on, my cough become serious. When I come with the morning sputum, she told to me to come back at 9 o'clock. I was annoyed because of commuting. I was told that the government institution was better. Is the service like this? I was disappointed a little. I thought to myself that private clinic would do everything for me. [...]"* (Young male)

### **Awareness and understanding of disease, attitudes and health seeking behaviour**

A few patients had been tested and/or treated for TB in the past and were aware of it being infectious<sup>Q3</sup>, of some of the symptoms and the possibility of relapse<sup>Q1</sup>. Other patients had relatives with TB<sup>Q2</sup> and knew what to expect of the diagnostic process. Other patients were unfamiliar with the disease symptoms<sup>Q4</sup>.

Examples of understanding of disease (patients completing diagnosis, IDI):

Q1 *"I received treatment before 3 years when I was sick. [...] I had the same feeling as I am feeling now with blood in my sputum. [...] It makes me cough during the night. I was sick with TB before, so I thought it relapsed. This forced me to come. In addition to this I assumed that my previous sickness replaced [had returned] when I saw blood in my sputum. So I came."* (Young male)

Q2 *"Some time ago, my brother was treated here. As he knows the procedure, he had told me that the sputum test might last for three days. So, since I was already aware of that, I hadn't felt bad about it."* (Young male)

Q3 *“there was a [TB] patient from our neighbour. I contracted the disease from the neighbour patient.”* (Young female)

Examples of lack of understanding of disease (patients completing diagnosis, IDI):

Q4 *“It is 15 days since it started. First when it started, I had pain in chest. I work in gymnasium. [...] My work is mostly related to dust. [...] The dust makes me cough. People tell me to drink milk. I did not stop when I drank fresh milk. It got worse and worse. I started feeling cold. I felt the sputum of malaria. I felt pain all over. [...] I went to clinic. I thought it would get better. It got worse starting from Saturday afternoon. I was sick the whole day on Sunday and I went to the clinic of my organisation for treatment.”* (Young male)

Some FGD participants had heard via the TV, radio and community campaigns that anyone having cough for 2 weeks should present to a health institution<sup>Q8</sup> and this prompted them to seek advice<sup>Q5</sup>.

Others commented that many mistake their symptoms for a cold or influenza<sup>Q7</sup> and delay attendance<sup>Q5-6</sup> until their condition has worsened<sup>Q8-9</sup>; even those who had heard the media announcements. Symptomatic individuals also delayed due to financial limitations and sought traditional medicine<sup>Q9-10</sup>. Participants commented that many people are not aware that the diagnosis (except the registration fee) and treatment are free<sup>Q9</sup>. Male patients explained they were too busy earning money to pay attention to their health, until it prevented them from working<sup>Q11</sup>.

Some patients knew of people that had recovered from TB after treatment and realised the disease was curable<sup>Q12</sup>.

Several TB patients referred for treatment had received treatment before and had relapsed. Having discovered what happened when they did not complete the treatment course, these patients expressed that they were very motivated to adhere to treatment. FGD participants registering for treatment mentioned that there was a common practice among the general public of closing windows on buses, to avoid contracting an illness from draughts, which they felt contributed to the spread of TB infection<sup>Q13</sup>. Some felt that there was more public awareness of HIV, than TB.

Examples of awareness and understanding, attitudes and behaviour (Patients completing diagnosis, FGD)

Q5 *"We have been hearing through different medias that if one's cough is prolonged for more than 2 weeks he/she should go for a TB check up. [...] there is usually a tradition of lagging from being treated on time. There is also a tendency of categorizing those who cough, as TB patients. It is thus in accordance to this, that I brought her here."* (Companion of female patient)

Q6 *"The society knows limited thing; they don't have deep knowledge about TB. They know that TB is the disease that has cough. [...] Sometimes while coughing they stay from one month to three months keeping quiet. Then when they become weak, they will be taken to the health centre on the stretcher. After getting better with treatment, some disappear."* (Female participant)

Q7 *"according to the tradition in our area, people who have contracted the TB are said to have caught the influenza. There is in fact the pressure in the rural area until the patient is taken by a stretcher, nobody considers the situation as a TB case. That is dangerous to the [...] family."* (Male participant)

Q8 *"There is an advertisement aired through the TV and the radio, which alerts by saying that 'If any cough prevails more than 2 weeks, it may be a TB case, so you have to go for treatment to the nearby health institution.' But the society does not give it any concern. They just take it as the influenza. In my area, except a few educated people who are suspicious about it, nobody has ever gone for a TB treatment. This big problem exists in the society. By being considered as an influenza patient, he will stay at home, until finally blood comes out when he coughs. Such negligence is a frequent event."* (Male participant)

Q9 *"I have neighbours. They have many children. All the family members cough. I told one of them that it might be TB so she should get medical treatment. She said that she had no money. I told her that it was for free. Then she went with my push. She went to referral hospital. There was something swollen on her back full of liquid. When that fluid is sucked by syringe the coughing. While her husband was coughing, their child also started coughing. When they are advised to seek treatment they say that there is traditional medicine. They cook and eat it. It seems as if they are feeling better. The illness doesn't stop. They say it is a cold so they try traditional medicine. Most of them do not know about TB. Few people know. [...] If they knew, his wife and children would not delay until they become ill. They don't know that the diagnosis is for free."* (Female participant)

Q10 *"There is no problem except the financial problem. In fact, now most take medicine they get in their area when they get sick, rather than consulting the health professionals. When the illness gets worse, they are taken to health centre or other place. [...] They receive treatment if they have money."* (Male participant)

Q11 *"I make a living running here and there. I did not think about my health. I think most of the time about my work. I don't go for treatment until it gets me down. Even I told my wife to go and receive the result. Unfortunately, it is worse than yesterday. So I left my job and came for everything. Nothing stops you from treatment except running for daily bread, I think."* (Male participant)

Q12 *"In fact, there are many of our friends who are sick were cured. There were times in which we run away of the patient. He was said to have died or was considered to be died. But now he got better, when he says 'It will be a lesson when he talks after he has felt better. We also realized that it is possible to recover from the illness by taking medicine."* (Male participant)

Examples of awareness and understanding, attitudes and behaviour (Patients registering for treatment, FGD)

Q13 *"I work for public transport. I am a driver. We hear on Radio or TV the windows of the buses should be open. When the windows are open there is disagreement among the passengers. They say: 'Do you want to kill us with cold?' so I stopped opening the windows. There may be TB patients in that bus. I was infected with that disease. They tell us to cover our mouth with cloth. No one covers his mouth with cloth when they get out of here. If the people see someone covering his mouth, they look at them with surprise."* (Male participant)

#### *Perceived and actual social impact of disease*

The stigma surrounding TB was a cause of patient delay and social isolation for FGD participants completing diagnosis. Fear of the social repercussions of the disease<sup>Q1,2</sup> caused patients to stay at home without informing others of the nature of their symptoms or their fears<sup>Q6-7,11</sup>. Once diagnosed, many chose not to inform those around them, isolating themselves and experiencing social rejection<sup>Q4-5,8-10</sup>. Stigma arose from the association of TB with HIV<sup>Q1-2,4-5,10</sup> (an assumption that all TB sufferers have HIV), fear that the disease was incurable<sup>Q3</sup> and of infection. Patients felt obliged to move out of shared accommodation and experienced physical rejection. One patient registering for treatment, on the other hand, was happy to share that he had HIV, but did not reveal he also had TB. His rationale was that HIV would be more acceptable to others as it cannot be so easily transmitted<sup>Q12</sup>.

#### Examples of social impact of disease (Patients completing diagnosis, FGD)

Q1 *"[...] nowadays, if some people with little awareness hear that someone is infected with TB, it is assumed that the man has HIV. So he does not want to be examined soon. People have little awareness other than hiding."* (Male participant)

Q2 *"nowadays if it is said TB, people fear that there is something in relation to it [HIV]. If it is said like that, the man isolates himself from the society and the society isolates him."* (Male participant)

Q3 *"As far as the society's awareness is concerned, previously they had no good image about TB. There wasn't any knowledge that TB can be cured through treatment. They felt even horrified of calling it by its name. It was even considered as [such] a serious matter if one uses its name in an insult. Nobody wanted to hear about it. But things are now better; this indicates that the society is now aware that TB can be cured through an appropriate treatment. A few moments ago, I came across with some people who, after seeing their result, asked me about the meaning of TB. When I explained them using the Amharic equivalent of the word, I saw them getting scared and shouting "Jesus!". This is an evidence of misconception that exists."* (Companion of female patient)

Q4 *"He denies it. Nobody tells that openly. [...]He does so because this time TB is a terrible disease. He may also be considered as having another related disease, because of these he avoids telling openly. Furthermore, he might be afraid of being isolated from the society. A few people may disclose their case but the majority don't do so."* (Female participant)

Q5 Companion: *“According to my understanding, my mother did not express her idea clearly. At present time an HIV patient shows a sign of coughing, both are related. An HIV check up goes with a TB check up. [...] people think that, if one affirms that he is a TB patient he might be afraid of being considered as someone who wants to deny the fact of his being an HIV patient. Sometimes people worry about what might be said about them instead of the big problem they have, this is in fact the reason why they don’t want to disclose the truth. They see HIV as a bad thing and do not know that it is possible to live with the virus. Indeed the fact of being isolated by friends and self isolation may exist but in the case of TB the situation may be improved when the condition of the patient becomes better after taking the drug. (Companion of female participant)*

Q6 *“[...] if I am found to be positive, I have a great fear that my friends would abandon me and that I could even be stigmatised by my family. Due to this, it is better to stay in self-isolation.” (Male participant)*

Q7 *“Now people are afraid of TB. My neighbour who was HIV positive knew herself. Now she infected by TB. Then, when she was near to complete the treatment, she told us. Most people do not talk about TB. I don’t know the reason. [...] We are not open for fear of being isolated”. (Female participant)*

Q8 *“I was very ill and became thin. I went to town council. When I stretched my hand for greeting they tried to shake my wrist not my hand. I was skinny and they discriminated me.” (Female participant)*

Q9 *“many people are anxious when they are told they have tuberculosis. [...] It is foolishness that there are some people who do not want their TB illness to be noticed. So they infect many people. This is bad. If someone is infected with TB among the family, he can infect others. It is good to get treatment on time.” (Female participant)*

Q10 *“if someone has TB people think that he has HIV. [...] people do not come closer to them. Especially there is a lot of problem with prostitutes, those who have family, their covers them. There are some who die of a cold and an illness. This is a problem. Some merely go to holy water and lastly die while they hide. Some say it HIV and some say TB. There is a problem if it said to be TB. I had a problem with those from whom I rented a room. If you go to holy water no one takes care of them. There may be a visitor for one or two day but on the other days no one will come to visit them. They miss meals. [...] For this problem they never talk about their sickness. If he can he tries to stand up to walk. But TB has a cough so it can’t be hidden. The cough exposes him.” (Female participant)*

Q11 *“they hide. If he found to be TB patient he is not regarded as a person. Others do not want to talk to them or sit with them and they run away from them.” (Participant)*

Examples of social impact of disease (Patients registering for treatment, FGD)

Q12 *“I tell people that I have HIV, but I don’t tell that I have TB. If I tell them that I have TB, they don’t allow me to come near to them. TB is transmitted by breath, so they isolate the patient.” (Male participant)*

### **Impact of illness on social and work relationships**

Few IDI participants completing diagnosis reported marginalisation or social rejection and reported family members being worried and concerned about their health<sup>Q1</sup>. Patients struggled to continue working to provide for their families<sup>Q2</sup> and those with children tried to hide the extent to which they were debilitated<sup>Q1</sup>. Reduced capacity to work reduced the household income, requiring family or friends to cover their duties at work, or work longer hours to cover the financial shortfall<sup>Q3</sup>. Patients were worried about how they could continue to care for or support their dependents<sup>Q1</sup>. One student felt pressurised to drop out of class, since his cough was drawing attention.

Examples of impact of illness on social and work relationships (Patients completing diagnosis, FGD):

Q1 *“My family are my children. They worry a lot when I get sick. They rely on me and they have no other hope. No one helps them. When they see me in bed they worry. Because of their worries, I just to walk outside [...]. I try to move here and there because of their worries.”* (Older male)

Q2 *“Though I was not forced to stay in bed, they were really affected because they solely depend on me. Therefore, since I did not totally stay in bed, I managed to bring home whatever I get from outside. So, ‘til now they are not directly affected. Instead, I was the one who was internally affected. They were worried because I was sick. They may also worry when I lose my appetite. As I am internally suffering they too feel bad and anxious, but they can’t help it. But as long as they are small children they soon forget everything and start playing.”* (Young male)

Q3 *“The members of my family are now constructing my elder’s brother house. My duty is control the overall process and to supply the materials needed for the construction. Since my brother is a driver, he cannot be permanently present at the site. In my absence, my friends are assuming my duties. The fact of not being able to help my family can be itself be considered as a negative consequence of my illness.”* (Young male)

Many TB patients registering for treatment described the social repercussions of the disease, from self-imposed isolation<sup>Q4</sup>, to being ostracised by relatives, friends and neighbours<sup>Q6,8</sup>, sacked by employers<sup>Q11</sup>, bypassed by customers and losing business. There was an assumption that patients were responsible for contracting TB due to an unhealthy lifestyle or unsuitable behaviour, as well as a presumption of positive HIV status<sup>Q6,7</sup>. Some patients chose not to tell those around them, or only a selected few, for fear of being marginalised<sup>Q4</sup>. Young patients had not told boyfriends or girlfriends<sup>Q9</sup>, and those who were single chose to remain unattached until they had recovered<sup>Q10</sup>. Others were relieved to be HIV negative and were happy to announce this to those around them<sup>Q7</sup>. Some felt a responsibility to be open about their disease status, in order to protect and educate

those around them<sup>Q5</sup>. Many found their family and friends supportive<sup>Q5,9</sup>. FGD participants made a distinction between rural and urban attitudes towards TB, finding city dwellers had more awareness of the disease and were less fearful<sup>Q12</sup>.

Examples of impact of illness on social and work relationships (TB patients registering for treatment):

Q4 *"In fact I hid myself for a short period of time. I did not show the medicine I was taking to anyone. When I go for treatment, I say: 'I will back.' [...] I am afraid of being isolated; the disease is communicable so they will not approach me."* (Young male, IDI)

Q5 *"I first told my family. My family knows all my secret. I myself [am] HIV positive. I discuss every[thing] openly with my family. [...] They feel sorry for me being sick, but they don't feel like isolation. In my view, it is me who should take care of them. But they are so sad for me being sick, because of additional disease. They say: 'You are HIV positive and how did you have additional disease TB?' They are very sad for this reason. Before this I took medication for 8 months and 6 month prophylaxis. [...] they asked me how I caught it the second one. [...] even I told them about HIV pandemic. I don't feel sad. I am taking care of them and it is what I should do. When I cover my mouth, people ask me if I have toothache. I tell them that I am a TB patient. 'I am attending treatment', I say to them. I have no feeling of hiding"* (Older female, IDI)

Q6 *"Some people thought that I had HIV. This is what happened to me. I was sick and in bed. They come to visit me and say that I should have treatment. I understood their feeling that there is another illness other than TB [...]. First I was angry. Those who did this are my relatives. [...] there some people who run away from me. They used to kiss me on my cheek but now they just hug me. They showed different behaviour from their previous one. This is because the disease is very serious, so they are afraid of it not to be sick I think."* (Young female, IDI)

Q7 *"I was very happy when I heard that I have the TB. I consider [name] Health Station just like my mother's child, because they detected my sickness. [...] Of course, I have to tell to everyone I must tell [that I contracted TB], for example to my friends. Because they were thinking that I was infected by HIV, I will tell to everybody that I have the TB. [...] They were very happy. Some of them said TB is connected to HIV and that I should go for an HIV test. Others said that this is a symptom of HIV, but I didn't worry. For me, the most important matter is to start medication after detection of my sickness, which has made me very happy."* (Young male, IDI)

Q8 *"I was isolated at school, but now they are comforting me. My friends were running away from me not to catch the disease. I make clothes by taking contract. It was stopped after I got sick. Now, after knowing that it will not be transmitted they approach[ed] me."* (Young male, IDI)

Q9 *"I have boyfriend, but he doesn't know that I am sick. Basically I started the treatment recently. He doesn't know that I cough. He did not know that I started treatment for TB. I tried to tell him, but he live away from me and we don't meet. He lives in Yergalem in my birthplace. [...] We get in touch by phone. My family give me amazing encouragement. They are taking care of me better than before. They regret thinking that they exposed me to the illness. My father regrets that it wouldn't be serious if I were treated earlier. My family are taking care of me."* (Young female, IDI)

Q10 *“maybe until I feel completely safe, I have no this kind of idea [marriage]. There is despise [contempt]. They may criticise me that I am patient. For this reason, until I become well I have no willing to marry. I want to make sure that I am safe, before I get into trouble.”* (Young male, IDI)

Q11 *“Now I am not working. I used to work for someone as housemaid. While I was working for someone, I did not feel comfortable. [...] My boss [...] the woman who brought me here from my place being my relative, started detesting me and told me to go home.”* (Young female, IDI)

Q12 *“Where there is technology and civilized people [...] people live with the patients without discrimination. [...] There were my friends from my place [in the countryside] who used to visit me. [...] After I told them, all my friends run away of me. They did not come to my house. [...] Those did not understand. They do not know about the disease. They would not behave like this if they knew that the disease could not spread by sitting and eating together. The people in the city eat with me. [...] [they] do not discriminate because of the awareness through technology and the health centre service. My friends came from the countryside that they don’t know about the disease that is why they run away from me.”* (Female, FGD)

### **Registering for treatment**

A key difficulty in attending treatment was the collection time for medication at the DOTS Centre, which caused patients to arrive late for work<sup>Q1-2</sup>. This caused problems with the employer – a situation sometimes made worse by the fact that the patient did not disclose their illness – resulting in ill-feeling, a reduction in salary, or even dismissal<sup>Q1-2, 7</sup>. The issue was particularly apparent in the FGDs<sup>Q2</sup>. Another difficulty identified by some FGD participants was finding a treatment supporter, since this implied revealing their positive TB status<sup>Q4</sup>. Like patients attending diagnostic services, patients attending treatment services were inhibited by the physical effort of attending while unwell<sup>Q5</sup> and the cost of transportation<sup>Q6</sup>. Patients were often compelled to travel with company due to a need for physical assistance, or in the case of females for cultural and religious reasons, thus increasing the transport costs<sup>Q6</sup>.

Examples of barriers to registering for treatment (TB patients registering for treatment):

Q1 *“I am a daily worker. I run here and there to make a living. I come here after assigning the workers to work. There are ups and down. I start work at 8 o’clock exactly. I also come here at 8:30 this is interrupts a lot with the cooperation of workers. I take my medicine and go back to work. [...] Sometimes my salary deducted because of my being late from work. Most of the time my employer complains for my being late for work; however, I must pay sacrifice for the sake of my health.”* (Male, IDI)

Q2 *“By the time the medicines are given, most people start to work at 1 or 1:30 o’clock. That is they are looking for their daily bread and they absent themselves. Here the medicines are given between 8:30 to 9:00 o’clock. I think they absent themselves because of this. Now I was dismissed from my job*

*for two months. I have 7 days more. My employers disappointment with my leave. The work of the flour mill is the morning. [...] There are some people who prefer work and be absent. [...] In a week, it would be good if we are given once. The difficulty is that it does not go with working hours. The pharmacy opens at 8:30 and goes to 8:40 – 8:50; we arrive at work after much work has been done. Most of us are employees. They do not allow doing a daily work because the arrival time for work is 1:30 o'clock. I work at flour mill so I can arrive at 9:00 o'clock. The arrival time is 8:00 o'clock. Every time they ask me why I get to work late. If I tell them why, they will isolate me so, I tell them that I wake up late from my bed. Also I tell them that I take physical exercises in the morning. [...] Most of the time I was kicked out of my job, because they said I could not do my job. They employed another worker in my place. I am working in another place and the same thing will happen again to me.”*  
(Male participant, FGD)

Q3 *“I was to go for educational practice. I was in trouble, because my family is far away from me. I cried much. I came and asked to have the medicine for a week. They said it is impossible. [...] One day I told them that I could not come the next day, for I had practice in the morning [and] I had examination in the afternoon. So I asked them to give the medicine for the next day. They refused to give, but they give to another person. Why they gave him and refused me? [...] What we call bad thing in the first place is the problem of being late for work. The patient may enter work or start school at 2:30, so they should open just at 2:30.”* (Female participant, FGD)

Q4 *“when I came for registration I was told to bring someone who can bail me out [supervise me]. I was living with my relative here for the sake education. If I bring my relative, she [the health professional] will tell him how serious TB is and how threat it is to his family. I am not their child, so I was afraid of being isolated.”* (Male participant, FGD)

Q5 *“another thing that makes the patients not to attend to their treatment is the getting worse of the disease. For this reason they can not commit to the centre to take the medicine daily and they quit it.”* (Male participant, FGD)

Q6 *“I cannot come alone. Somebody should come with me. For both of us double trip we spend 12 birr[...] I can't keep my balance, so my mother comes with me to support and the expense is a big problem.”* (Participant, FGD)

Q7 *“some people work in private organization. They do not get permission to leave their work. There is a probability of dismissal from work. This can be barrier.”* (Male, FGD)

#### *Reasons for not registering for treatment*

Two male patients not registering for treatment agreed to be interviewed. One 70 year old patient<sup>Q1</sup> had refused to be interviewed and wanted to keep his illness hidden, as it would be associated with HIV. The patient knew some of the staff at his local DOTS centre and he decided not to register, as he knew they would tell others and the news of his illness would spread. The patient had not informed his wife or children. He preferred to stay at home and die, rather than divulge that he had TB. He was no longer able to work his land, planting coffee and inset (false banana), and had handed it over to others, who shared the profits with him. His condition had deteriorated and

he was confined to bed, but continued to tell visitors that he was getting better. He was constrained by lack of finances, the distance to the health centre (one hour on foot) and weakness. The patient did not seem aware that that TB was curable and had no knowledge of the treatment duration and decided to register for treatment after the interview. The second patient, a 35-year old male<sup>02</sup>, was primarily constrained by his physical condition and inability to reach the health centre, either on foot (one hour over hilly terrain) or public transport, due to lack of money. He had lost business as a chat seller. His family was not supporting him to attend the health centre, feeling they had already contributed by taking him to Awassa for diagnosis. He had only informed his immediate family of his disease as he was afraid of being stigmatised by those around him.

Examples of reasons for not registering for treatment (TB patients not registering for treatment):

Q1 *“When I was told that I have the disease, I have no potential to get treatment. The place is also very far away. Another thing is that I did not tell my wife and children about tuberculosis. The reason is that if people hear that I am sick, they think that I have HIV, so I did not want to tell anyone. If I die, let me die without ruining my name, so that I kept secretly until now. Our people like fabricating news. If I tell for someone, he will tell to another person. The news will cover the country. Thus is why I refused to tell you last time. Later, after he came and explained to me by health extension workers and kebele leaders, I agreed to tell you for the first time. [...] What hindered me is that the first thing I have no financial capability to have treatment. I also lost strength to go. The main thing is that if I go, there are some people working there who knows me. If they become aware of my sickness, they may tell other people. Come what may, I better stay at home and die. That is why I didn't registered. [...] it takes one hour for the person like me on foot. Cars are not available but horse carts are available. We pay 6 Birr round trip. This is as far as Tula town. The health centre is outside the town so that fare goes to ten Birr.”* (Older male)

Q2 *“soon after I came back from [Awassa], I was very sick. I was so weak that I had even lost my energy of moving and walking. In addition to this, I had no money to cover the cost of transportation to reach there [the health centre for treatment]. [...] If one walks it will take him more than one hour. As you have to go across a big hill it is extremely difficult to climb it, especially for someone as weak as I was. By bus, it costs 2 birr for a single trip and 4 birr for a round trip. When I was healthy I used to walk several times. But now I can't do that. [...] I told to my wife and my brothers. I repeatedly said that I was about to die and begged them to take me for treatment, but they reluctantly replied to me that they had already taken me once to [Awassa]. [...] Practically they didn't want to take to the clinic, but no one directly opposes my idea.”* Since I am a weak sick person, I failed to go for treatment. [...] Because of my sickness my business is affected. My revenues have gone down. I am no more active. Because this I did not go for treatment.” (Younger male)

## Suggestions for improvement

Focus Group participants completing diagnosis made suggestions to facilitate patient attendance and adherence. These included improving the health professional's bedside manner to ensure positive patient experiences and increased patient awareness and knowledge of TB<sup>Q1-2</sup>. Improving the rapport was felt likely to increase patient confidence in the staff and facilitate completion of the process<sup>Q1</sup>. Patients having positive experiences would feed back to the community, raising the profile of the Centres and encouraging other individuals to attend<sup>Q1</sup>. Changes to service delivery included ensuring a same day diagnostic process and allowing patients that could not attend to send sputum samples via another person<sup>Q3</sup>. Ideas to increase public awareness included providing health education about TB<sup>Q4</sup> - its symptoms, transmission routes, the availability of free treatment<sup>Q4</sup> and importance of treatment adherence; using public gatherings, religious meetings, schools and mass media as platforms for communication<sup>Q5-6</sup>. Other suggestions included peer educators and targeting services to the poorest and most vulnerable sections of society<sup>Q5, 7-8</sup>.

TB patients registering for treatment suggested increasing the number of diagnostic and treatment centres to facilitate access<sup>Q9, 10</sup>, seeking new cases among family contacts<sup>Q10</sup> and recruiting TB patients who had completed the treatment course as peer educators or champions<sup>Q9</sup>. Peer educators would give health education to newly registered patients about TB medication and dietary advice, alongside health professionals<sup>Q9</sup>. Many FGD participants suggested staff should come earlier to allow patients to collect medicines without interfering with their work schedule. Others requested treatment doses to be given for several days<sup>Q15</sup> (using the treatment supporter if necessary), to alleviate transport and opportunity costs, the physical burden of attendance<sup>Q10</sup> and friction at work. Providing an in-patient service for those too ill to commute<sup>Q10</sup>, was also put forward. TB patients registering and not registering for treatment proposed providing transport to the treatment centre<sup>Q14</sup>.

Suggestions for improvement (Patients completing diagnosis, FGD):

Q1 "I [have] three suggestions. The first [...] is the love the professionals have for the patients. Their feelings and approach to the patient makes the patient feel that he will get solution for this illness. So the trust the patient has in the health professional will help the patient to follow his examination and complete it as a result of good hospitality. The other is [...] his own or his family [situation] after examination. If [he has] trust in this health institution he will say to others: 'Go there and get medical examination.' [...] The [third is] if he is aware about the disease and understands how harmful the disease, he will complete the medical examination." (Female participant)

Q2 "The nurses and other professionals who work here should be given special training on how to show hospitality. [...] When I come here being taken ill, the advice I get from the profession is much better than money. It would be good if they are trained on how to treat patients." (Female participant)

Q3 "We commute between [the HC] and our home spending money. [...] those who can afford come here who cannot afford cannot come. So, who can afford comes 2 or 3 days for sputum test. Who cannot afford can send through someone or it would be good if arrangement is made to complete it in a day. Rather than prescribing sputum test today and X-ray tomorrow, it would be good if a person suspected receives sputum test and X-ray in one day." (Male participant)

Q4 "[...] when I was a student of grade 7. There was a girl [...] who was coughing. Her family could not afford to take her to a HC. The main thing was that they had no awareness. If it was today I would take her to a HC. Lastly she died. [...] the society does not have awareness, so it would be good to give health education about the disease. Who knows that the treatment for TB is for free? Someone [who] was treated only. I suggest [...] it is announced that the treatment is for free." (Female participant)

Q5 "It is good to raise awareness like HIV about TB on different meetings of public and religious meetings. It is good to raise awareness about the treatment means, way of transmission, and prevention methods in the rural areas for the peasants. [...] many people dying of this disease are children, youth and old people. This disease is related to lack of capacity, so, [...] rather than watching while someone dies, I suggest that it would be good if the organisation identify poor people who are affected by the disease to get access to medical service. People living with HIV AIDS openly teach about the disease where people are gathered. I think it will be good if TB patients do the same thing." (FGD Participant 1)

Q6 "I think it is easy to raise awareness at the religious institutions and public gatherings. It can be done at schools. It is possible to strengthen this idea to be continuous through mass media." (FGD Participant 4)

Q7 "I suggest that people should be selected and be given training so that they teach the society." (FGD Participant 2)

Q8 "[...] They should tell the whole story how they were before they were infected and after they infect by the disease. When people hear the experience the affected person, they understand the disease. If this is done through kebele, all people will access to the lesson." (FGD Participant 5)

Suggestions for improvement (TB patients registering for treatment):

Q9 "Some patients came from distance [to collect treatment]. There are some from Dato. The government should establish in the vicinity. For example it would be good if 4 to 5 health centre are constructed in Awassa. The transportation is difficult when you come from distance. [...] regarding TB is that it would be good if attention is given like HIV health education is given. Last time I was happy when the health education is given. I was not told anything when I started treatment. When I

*got sick on Saturday and Sunday I said: 'what shall I do?' My family asked me what the health professional said. I told them that they did not say anything. I should have been told what to do when I took 60 injections. So giving health education is very good, because most do not know what to do. When the previous patients finish their treatment, it is good to give health education for new patient. What kind of care should the patient take regarding the kind of food they should eat. However, they need some advice from health professionals." (Older female, IDI)*

*Q10 "I suggest that the health centre should not be only this one; there are some people coughing and having the TB symptom who do not seek treatment. This kind of people should be hunted to get treatment. For example, I, my family and my friends had medical examination. In the same way the health centre should take responsibility for the other families. It should be said that bring someone with cough in your family to the health centre." (Young female, IDI)*

*Q11 It would be good if the service is given there." (Male, IDI)*

*Q12 "those who are seriously sick should stay at hospital and attend their treatment. [...] Such kind [of] people should be hospitalised, otherwise they face problem in commuting." (Male, FGD)*

*Q13 "I suggest that weak people who come here for treatment should get medicine for a week through a person stood bail for [supported] them." (Male, FGD)*

*Q14 "it would be good for the health centre to have a bus. The bus can collect the patients from different areas to enable them to get treatment." (Female, FGD)*

*Q15 "With regard to TB medicine, it would be nice if the medicine is taken home. It will minimize transportation expense for the patient." (FGD)*

#### Synopsis: main enablers and barriers

In summary, participants indicated that having sufficient financial means, receiving financial support from an employer or relative and being well informed about the diagnostic process and its duration facilitated attendance at diagnostic services. Patients who had been recommended the health centre and had, or had acquaintances that had, been diagnosed and treated, felt reassured and were more willing to attend. Relapsing patients, often associated with having defaulted treatment, were also more convinced of the importance of completing diagnosis and medication. Having a supportive family and friends and work environment were also enablers for diagnostic adherence and treatment registration. Living in the city, which was considered to have a more progressive and better informed population, was viewed as a protective factor.

The cost of attendance, poor staff attitude, the attraction of the private sector and the difficulty of returning for a second day, were the most important barriers to diagnostic attendance.

Geographical distance and physical illness were further inhibitors cited by participants, as well as fear of the disease and accompanying stigma.

## **Discussion**

Patients with symptoms compatible with TB often present late to diagnostic services in Ethiopia.

Although reasons for delay in presenting to diagnostic services and for defaulting from TB treatment have been documented in Ethiopia (Demissie et al. 2002; Sagbakken et al. 2008b; Yimer et al. 2005), little is known about the reasons for patient drop out *during* diagnosis, nor conversely the factors that enable some patients to complete, while others default.

The qualitative study provided valuable information about patients' experiences and views and further developed the information obtained through the quantitative surveys (chapters 4 and 5).

The use of two research tools was useful, as individual interviews portrayed personal experiences, while the FGDs encouraged participants to share experiences and often elicited views that were not clearly expressed in one to one meetings. In addition, the juxtaposition of two cultural settings such as Yemen and Ethiopia allowed identification of similar and contrasting experiences faced by patients.

Patients defaulting diagnosis or not registering for treatment proved difficult to find and were reluctant to participate in the study. Therefore the study had the limitation of having included only a few interviews of patients not registering for treatment. The views of the participants, however, provided many insights that enhanced, qualified or illustrated the survey results and thus the use of a combination of research study designs and methods enriched the research presented here.

### Main barriers

#### *Cost of attendance*

The cost of attending the services was a key barrier to completing the diagnostic process. The principal cost components identified in the quantitative study (transport and clinic fees) were further qualified here. A large majority of Ethiopian patients in the survey attended with company.

Like patients in Yemen, companions provided much needed moral and physical support, but increased the direct costs, of which a substantial portion was presumably for transportation. Surprisingly, participants indicated clinic fees were affordable; however the cost of non-TB medications were beyond their means. Unlike participants in Yemen, Ethiopian participants were infrequently referred to the private sector. Although private medicine is locally available and patients often seek their services, one possible explanation is that the health centres provide services for a range of conditions, while the centre in Yemen was a TB centre with a limited number of laboratory tests. Expenditure for patients, however, was still significant and in agreement with findings of previous studies (Cambanis et al. 2005a; Cambanis et al. 2007), many patients felt compelled to sell assets, use savings, borrow money and incur debts to fund their attendance. Moreover, many patients indicated they had lost revenue through absence at work.

#### *Attitude of staff*

Participants often referred to the poor treatment by staff, which ostracised patients and were regarded as disrespectful, lacking in empathy and discriminatory against patients with a poor physical appearance. Participants were critical that not all physicians performed a physical examination. Poor staff attitude was signalled as an important obstacle to diagnostic completion and was often accompanied by a lack of confidence in the competence of health professionals. Participants felt that off-putting staff behaviour could be a key reason for other patients dropping out. Loss of confidence in the expertise of health professionals constructs a poor reputation for the health centre in the community and perpetuates non attendance or delay (WHO 2005), as well as contributing to patient default rates. In contrast to Yemen, there were little or no reports of financial deceit, requests for unofficial payments or referral to private clinics.

#### *Private medicine*

There was a common perception that the private sector provides better and more efficient services with longer opening hours, which led many patients to delay attendance and feel tempted to abandon the process. In this region, private practitioners provide a 7-day a week service, often until

late at night, which makes them attractive to patients - although at a price that is beyond the means of most patients. The study thus confirmed findings elsewhere in the literature (Sagbakken et al. 2008b; WHO 2005), that many people in the community delay attendance until their condition becomes critical; due to financial constraints and a reliance on private and traditional medicine.

#### *Gender*

There was recognition by female and many of the male participants that women, in particular rural women, faced particular obstacles to diagnostic attendance and completion. Many women were said to hide their illness from their husbands and faced difficulties to leave their household and childcare responsibilities. Within a traditional role, women do not have access to household finances, need permission from a male to seek healthcare, can rarely travel or attend unaccompanied and worry about neglecting their duties at home (Diwan and Thorson 1999; Ottmani and Uplekar 2008; Sagbakken et al. 2008b; Sanou et al. 2004a; WHO 2005). Women therefore experienced particular difficulties to attend, but perhaps less so than female patients in Yemen, whose portrayal of differentiated gender roles was starker.

#### *Returning for a second day*

Several participants indicated that the need to return to the health centre after the first day was a major barrier to completion, which is similar to other high TB burden settings (Squire et al. 2005). Many patients expected to receive tests results the same day and to return home with a diagnosis and did not understand why the process could not be completed in a day. These expectations, together with their physical limitations and concern about lost revenue, were strong inhibitors and many participants had considered abandoning the process or knew of others that had done so.

#### *Attitudes and social stigma*

Many participants indicated that failing to realise the serious nature of the disease and fear of TB and its negative social consequences, were further reasons that patients might abandon the diagnosis. Indeed, the social stigma surrounding TB was a cause for patient delay. Participants feared marginalisation due to the perceived risk of infection among peers and the prevailing view

that TB is easily passed on, incurable or associated with HIV. The latter is also a common association in other settings, especially in populations with a high incidence of HIV (Gebremariam et al. 2011; Kipp et al. 2011). The social stigma surrounding TB was also perpetuated by staff, who avoided patients and treated them with contempt, telling them to sit at a distance and not to cough in front of them.

#### *Barriers for treatment registration*

Similarly to diagnostic attendance, key barriers for treatment registration were the reluctance of patients to reveal having TB, their physical weakness which limited their ability to attend treatment centres to collect daily medicines, difficult physical access and distance to the centres, and financial constraints. Patients often highlighted that the treatment collection time made them late for work, as they travelled on to work in the morning from the centre. This had negative repercussions for their income or relationship with work colleagues. Working patients indicated they were often late for work, but were reluctant to disclose the reasons for this and faced problems with their employers. This is an important issue that could be avoided as, in other settings, treatment has been successfully decentralised to closer locations to the patient, such as corner shops or chemists, neighbours and others (Wei et al. 2008) and are worth exploring in Awassa. Similarly, the Health Centre is closed for 3 or 4 weeks in the year, to allow staff to participate in national vaccination campaigns. These closures can lead to disappointment for uninformed patients, as reported in this study and impede treatment collection.

#### *Experience of diagnostic services*

Although patients generally indicated being satisfied with diagnostic services, when probed, many patients were critical of the substandard organisation in the card room, queue management, work ethics of staff and overcrowding. Approximately half of the patients found the diagnostic duration problematic. Patients suggested the provision of training to improve the health professionals' bedside manner, which would lead to improved communication and information giving. Although some patients felt well informed and had a clear understanding of their diagnosis, others wanted

more health information, particularly those with a diagnosis other than TB. Many of the latter would have liked an explanation of the rationale behind repeated tests and visits. This is an important issue often dismissed by TB diagnostic services. Only a minority of patients screened for TB are eventually confirmed to have TB (typically 10-20% in a high burden setting) (Cuevas et al. 2011b). Most patients attending the clinic therefore end up with a “*not-TB*” diagnosis and are given a prescription of antibiotics and asked to return if symptoms persist. Thus, most patients attend the laboratory for several days, provide multiple samples and are finally told they do not have TB. As most patients seek out health services because of the symptom of chronic cough, and not for a specific disease (TB), they are often disappointed to have a *negative* diagnosis. It is very likely that improving patient satisfaction and perception of service quality will require the provision of health information that is more responsive to the expectations of patients, the majority of whom receive a vague, clinically-based diagnosis that warrants careful explanation.

#### *Miscellaneous causes of service dissatisfaction*

Patients also indicated that there is no triage system to prioritise infirm or elderly patients in the Health Centres. However, at the time of writing this thesis, training was being introduced to separate chronic coughers and introduce a triage system. Patients also complained of some patients being seen earlier than others. Currently, patients’ registration cards are divided between the doctors (e.g. 20 cards are divided between 4 doctors, allocating 5 cards to each). If a doctor has simpler cases and sees patients quickly, this is likely to create the perception that the system is unfair, as a patient arriving later could be seen earlier. However, it is also possible that the cards in the card room become muddled. Although the number of daily cards distributed at the time of the study was limited, the situation has now changed, as Awassa Health Centre became a 24 hour hospital.

At Awassa HC, laboratory results are given out progressively; while in Bushullo results are collated and given all at once. Patients at the latter complained, as it seemed unfair to wait longer than

someone who had arrived later; however the laboratory is busy and slides are processed in batches. In addition, government Health Centres do not accept sputum test results from the private sector (as the quality of the smears is not monitored and varies) and thus request confirmatory sputum tests; a practice which can lead to frustration among patients. Another complaint was charging for X-rays. About two-thirds of patients with chronic cough in Bushullo HC are sent for X-rays. Patients diagnosed with TB are then reimbursed. Although many patients prefer a chest X-ray to sputum, they are often disappointed at the charge.

#### *Suggested improvements to services and public awareness*

Ideas put forward to increase public awareness of TB, included the provision of health education using peer educators, public gatherings, schools and mass media as conduits. Participants also suggested targeting services to the most vulnerable sections of society. As previously highlighted, patients suggested several changes to treatment services, namely: earlier opening hours at DOTS centres to allow for timely distribution of medication and minimal disruption to work, the provision of transport services for TB patients, allocation of medication for several days to patients residing in remote locations with few resources and active case finding of patients with confirmed TB. Many patients also suggested changes to service delivery, including increasing the number of diagnostic and treatment centres to facilitate access, achieving a same day diagnosis and allowing patients unable to attend to send sputum samples via another person. These sentiments accurately reflect the long distances patients travel to access diagnostic centres and the relatively small number of centres for a 14 million population. Although TB services have rapidly expanded since the start of the DOTS programme in the region in 1994 (Yassin et al. 2006), the predominantly rural profile of the population (2010a) often finds patients using private transport on small, unpaved roads to access diagnostic facilities. The decentralised DOTS strategy, implemented in recognition of the fact that a key method of improving treatment adherence was to make treatment readily accessible, cannot be extended to diagnostic facilities. A basic laboratory infrastructure is required and

diagnostics suitable for remote facilities are lacking (McNerney et al. 2012). Diagnostic centres therefore remain more centralised than treatment centres.

#### Methodological constraints

During the course of the study, it became clear that patients following the *spot-spot-morning* scheme were disadvantaged if they were smear-negative, as they waited the first day to receive a test results at 3 p.m. and then were asked to return to submit a third sputum. This was an unintended negative consequence of the scheme, which, since the majority of patients are smear-negative, was quite important.

The intended implementation of the 2-smear scheme (WHO 2007a) had not been adopted in Ethiopia, as it takes several years to revise national guidelines, and thus we were unable to implement these changes during the course of the study. Patients therefore did not experience a tangible difference between 3 smears taken in a slightly different order, since both schemes took at least two days for the majority of patients.

Another limitation is the lack of IDIs with patients defaulting diagnosis and only two IDIs with patients not registering for treatment. Considerable attempts were made to trace and secure interviews with patients defaulting from diagnosis and failing to register for treatment. The local research team contacted patients recorded as defaulted by telephone and found that many had in fact received a first day diagnosis of “not TB”, been prescribed antibiotics and told to return to the Health Centre if their condition did not improve. Thus, as in Yemen, some physicians had made a same-day clinical diagnosis based on 2 smear results and chest X-ray.

As for patients not recorded as having registered for treatment at their chosen Health Centre, the team began to work with Health Extension Workers (HEWs) in an attempt to trace missing patients. The researchers travelled with the HEW supervisor to each health post, held a discussion with the HEW and gave them a list of patients’ names. The HEWs reported back whether or not the patient had been found in their *kebele*. Further, under the responsibility of each HEW are health promoters,

who are responsible for 50 households. The HEWs asked the *kebele* health promoters to search for missing patients and fortnightly rounds of IDIs were conducted with those that were identified. Health facilities of neighbouring districts were also visited and some patients were found in this manner. Eighteen of 25 TB patients not registered for treatment at the indicated Health Centre had registered at a different centre and 6 cases were never traced. Problems encountered included confusion with names, inaccurate telephone numbers or addresses, the majority of (particularly rural) patients not having a landline and poor mobile network coverage.

Women were underrepresented in the IDIs. Although women in IDIs did not report particular difficulties to attend diagnosis, FGDs provided a platform for women to express themselves freely, find courage in numbers and pool ideas, particular the FGDs in which only women were present. However, it was enough for one male patient to say that women and men had equal access, to end the discussion.

There was also an imbalance of urban to rural participants, despite a predominantly rural population. Since rural residency is likely to be a key barrier to attendance, this might have produced findings which underreported barriers faced by the rural community.

Finally, some FGDs combined male and female, older and young patients, which, given the hierarchical structure of this society is likely to have restricted the contribution and content of the discussion by female and young participants.

### **Conclusion**

This qualitative study supported the survey findings described in chapter 4, highlighting that cost is a major constraint to attending diagnostic services. The study revealed a number of additional barriers and provided an insight into the interplay between constraints to attendance, with harrowing descriptions of destitution and crisis. The IDIs identified that in addition to the cost of attendance, patients were concerned about losing revenue through absence at work and the threat of dismissal. Distance to the health service and ill-health were also important inhibitors. In addition, participants (especially in FGDs) often reported poor treatment by the centres' staff, lack

of confidence in the health centre and being drawn to the private sector. Women had specific difficulties to attend due to caring and household responsibilities and often had to negotiate with their partners and male relatives. Most participants attended with company, which increased the cost of attendance and found it particularly onerous to return for a second day of diagnosis. Many were also dissatisfied to receive an unspecific diagnosis other than TB, highlighting that patients often feel more reassured to have a disease whose treatment is well-established than a diagnosis with an uncertain path to good health. The study also identified that participants were greatly concerned about how they would be regarded by others, due to the stigma attached to TB, and – as shown in the surveys - were only prepared to disclose their diagnosis to close family members, with very few revealing their status to work colleagues and employers. The unwillingness for disclosure stemmed from patients' experience of dismissal from a salaried post, deselection for daily labour and lost business. The lack of transparency created conflict with employers, as patients had to travel to receive treatment, but were unable to explain why they were late to start work in the mornings and has implications for spread of the disease, as patients share significant contact time with colleagues, which can lead to secondary infections. Participants gave valuable suggestions for improving diagnostic services, many of which centred on staff attitude and training, information giving and simple organisational changes, which would be relatively inexpensive. Many of the barriers are harder to remedy, requiring health policy changes, considerable investment, restructuring of health services to bring them closer to the community and financial support for patients.

## **Chapter 8**

### **Discussion**

This study set out to identify and describe the range of difficulties faced by patients attending TB services to access diagnostic services, complete the diagnostic process and, where appropriate, begin TB treatment, by means of cross-sectional surveys, in-depth interviews and focus group discussions in health settings in Asia, Africa and the Middle East. Factors that facilitated patient attendance were also identified. As seen in the literature review in chapter 2, few studies have explored the difficulties associated with attendance for diagnosis, but rather have concentrated on the difficulties faced prior to attendance (usually with a focus on the duration and reasons for patient delay) or during treatment. This research was particularly interested in the patient experience during the few days of diagnosis, against a backdrop of testing the feasibility of an accelerated diagnostic scheme, using a same day, 2 sputum smear process, as described in chapter 3.

The study began with an exploration of the financial cost of attendance at TB diagnostic services, through a cross-sectional survey of 2225 patients on their first day of attendance at TB diagnostic services in Ethiopia, Nepal, Nigeria and Yemen. This was followed by a second survey of 1106 patients on their first and second day of attendance, to identify the non financial barriers to attendance at diagnostic services in Ethiopia and Yemen. Both surveys used a structured questionnaire. The last study phase was a qualitative exploration of the barriers and enablers for diagnostic and treatment attendance via 121 semi-structured IDIs and 23 FGDs with patients completing and defaulting from the TB diagnostic process and registering and not registering for treatment, in Ethiopia and Yemen, which complemented information obtained in the earlier studies.

As intended, the employment of a mixed methodology to address the research question proved complementary. The qualitative studies uncovered many new aspects of patients' experience at TB services which had caused concern or difficulty, but had not surfaced using quantitative techniques.

In particular, patients were reluctant to be critical of services or staff during the quantitative phase. It is possible that the structured, rapid response style of a survey did not allow sufficient rapport to develop between the interviewer and research participant to enable honest answers to sensitive issues, that patients were reluctant to criticise without explanation, or that they had low expectations of services and had professed themselves to be generally satisfied within these narrow parameters. Measuring patient satisfaction through surveys is notoriously prone to methodological limitations. Furthermore, the difficulties faced by women did not emerge in the survey. The more flexible nature of the qualitative studies also permitted greater insight into the structures and circumstances which create unequal access to TB services and consideration of how they might be addressed. Lastly, the study in Yemen is essentially unique in employing qualitative methods to explore the views of adults attending TB diagnostic services.

#### *Patient characteristics and study settings*

The study settings were chosen for their location in countries with a high disease burden, their situation in diverse geographical regions and for the working links that had been established between academics, managers and health professionals in the host institutions and the research team at the School of Tropical Medicine in Liverpool. There were inevitably some differences in the study settings. Abuja is a newly built city, home of the government and attracts many well educated people. Nevertheless, many of its residents, including construction workers, live in urban slums. Public transportation is not well developed and the city has a sprawling population covering a large area, with many unofficial settlements on the outskirts. The patients attending the government general hospital will be those without financial means, but a higher proportion of Abuja residents will be skilled and in employment than residents of other towns in the country. Kathmandu, in contrast, is a compact city whose boundaries are better delineated. A portion of the participants in the study documenting patient costs in Nepal were recruited via a private clinic and thus were likely to be better educated.

Despite the differences in the populations served by the study settings, there were many similarities in the findings between the four countries. A large proportion of patients enrolled in the cost survey in Ethiopia, Nepal and Yemen lived outside the city in which the study clinic was located. With the exception of Nepal, patients had to travel for a considerable amount of time. The number of patients attending from another location could be indicative of a paucity of local health services with diagnostic facilities, poor patient knowledge of services, patients attempting to reduce the risk of social stigma by attending services far from home or the good reputation of the participating health centres. Patients in Nigeria and Nepal had higher literacy than in Ethiopia and Yemen. The second survey showed normal variations from the first survey in participant characteristics, as might be expected from one study to another. In particular, there were variations in patient occupation, a lower proportion of men in Yemen and a lower proportion of rural residents and higher literacy levels in Ethiopia. Patients lived in large family groups, particularly so in Yemen and a minority of patients were born outside Yemen, mostly in neighbouring Somalia. Some of the differences might be explained by seasonal attendance patterns, for example attendance at health services by farmers may fluctuate in line with crop planting and harvesting. In the qualitative studies, more male patients and more urban residents were interviewed in Yemen and more rural residents in Ethiopia.

### **Costs associated with diagnosis**

Despite the international policy goal of ensuring universal access to free TB treatment, the financial and broader economic consequences of TB for patients and their families are known to be immense, many of which have an impact before a formal diagnosis is reached (Kemp et al. 2007; Lonroth et al. 2007; Mauch et al. 2011; Yan et al. 2007; Zhang et al. 2007). Although many studies have described the cost to the patient before attendance at TB diagnostic services and/or during treatment (Umar et al. 2012; Vassall et al. 2010), few have described the costs specific to diagnostic attendance at a health facility that is part of the NTP or subdivided costs into their various components. The quantitative study gained an overview of direct costs incurred by patients across several countries and compared expense patterns between country contexts. The survey was

unusual in employing the same methodology across several study settings, distinguishing between first and second day expenditure and exploring the use of a score to identify patients at risk of higher expenditure. The qualitative studies provided an opportunity to explore unanswered questions raised in the quantitative study, offering a valuable insight into the reasons for the high expenditure of patients from rural areas and other towns and, in Yemen, the nature of the unspecified costs, which had constituted a large proportion of expenditure for a minority of patients. In both countries, patients' narratives provided an indication of the indirect costs and wider economic consequences of attendance for diagnosis and treatment.

Where the individual components of patients' direct costs have been investigated in the literature, studies often report costs in relation to the period from onset of symptoms to the diagnostic or treatment period and combine costs incurred by patients in the private, public and informal sectors (Karki et al. 2007; Kemp et al. 2007; Umar et al. 2012; Vassall et al. 2010; Wyss et al. 2001). This survey, however, indicates that the direct cost of attendance for diagnosis is in itself significant. The most important costs incurred by participants in the four countries, were for clinic fees, transport and miscellaneous expenses. The proportion of expenditure on each component varied from country to country. Patient narratives from IDIs with patients in Ethiopia and Yemen confirmed that the most important expenses for patients were for transport and clinic fees and, in Yemen only, miscellaneous costs.

The cost of transportation from home, or from a temporary place of residence, to the clinic constituted an important part of patient expenditure, which supports the findings of a previous study of reasons for patient delay in rural Ethiopia, where patients spent an average of 12 ETB (US\$1.40 as of the exchange rate in May 2004) on transportation to reach the health centre, with a journey time of approximately 5 hours (Cambanis et al. 2005a). In the current study, the proportion of money spent on transport seemed to vary in line with patients' travel time from home.

Transportation costs in Sana'a were further increased by the location of the NTI beyond the limits of

the public transport network and the frequent referral by staff for additional tests, which required travel to private laboratories. Transportation costs are known to be a significant barrier to accessing diagnosis and treatment (Karki et al. 2007; Mauch et al. 2011; Wyss et al. 2001) and reflected the fact that many patients travelled from outside the locality to attend the clinic, although some patients travelling locally also found the cost of transport prohibitive. A considerable portion of additional expenditure for being accompanied can be attributed to the cost of transportation.

In Yemen, the miscellaneous costs included tests conducted in the private sector, prescriptions, private consultations, unofficial payments to staff and the acquisition of Qat. While in Ethiopia there were little or no reports of financial deceit, requests for unofficial payments or referrals to private clinics, the problem of under-the-table payments, overcharging, extra payments in return for an enhanced service and individual profit-making by some staff members is by no means unique to Yemen. There are few reports of underhand payments or overcharging to health or administrative staff specific to TB diagnostic and treatment services, possibly because it is sensitive to document and report. Wyss et al. mention the need for patients to make informal payments in exchange for TB services within the Tanzanian NTP (Wyss et al. 2001). Otherwise, there are reports of impropriety at government level impeding the delivery of healthcare or health programmes (Hargreaves 2002; Udawadia 2001). Hanf et al., in an international study of secondary data, linked the levels of corruption and of MDR-TB in a country, principally in relation to the regulation of product quality and distribution and use of drugs (Hanf et al. 2012). A small step which could aid financial transparency could be the posting of itemised clinic prices in a visible location at the clinic entrance or registry.

Clinic fees were also substantial and patients were charged variously for registration, X-rays, consultation fees and smear tests, as reported elsewhere (Karki et al. 2007; Umar et al. 2012), with the exception of Nigeria, which offered free smear microscopy. The qualitative study clarified that patients considered the cost of non TB medication and additional tests in the private sector, to be

part of clinic fees, therefore although the cost of registration was considered reasonable, in combination with other costs, clinic fees were unaffordable for some, and in Yemen it is likely that some patients were overcharged. In Ethiopia, patients were troubled by charges for X-rays and non TB medication.

Patients spent little on food and few paid for accommodation, with the majority of non residents staying with relatives. The cost of food has been reported to account for the most significant proportion of patient expenditure after transport costs during the treatment phase and the pre-diagnosis/diagnostic phase (from onset of symptoms to diagnosis at a public health facility) in a study in Kenya (Mauch et al. 2011) and in Nigeria constituted a considerable part of total costs (Umar et al. 2012), but expenditure on food pertaining to the few days of diagnostic attendance has not been described. Although a previous study reported patients planning to stay overnight (Cambanis et al. 2005a), there are few reports in the literature of patients paying for accommodation. In Kenya, expenditure on accommodation was negligible during treatment and not reported at all by patients before a diagnosis was obtained (Mauch et al. 2011). It is possible that patients attending TB diagnostic services are able to attend in part as a result of having family or friends living in the town or city in which the clinic is located. Conversely symptomatic adults without such social resources may feel constrained to stay at home or seek alternative solutions. Many Yemeni patients stated that staying overnight was problematic. It is not known whether this was a result of opportunity costs arising from absence from home, the additional cost of a second day, or the need to make a financial contribution to relatives to cover the cost of staying. This may be a neglected area of research.

Many patients had lost revenue through absence at work and missed earning opportunities. Yemeni patients also mentioned financial losses from unpaid sick leave. Patients in Ethiopia highlighted that treatment collection interfered with their work schedule, placing them in a vulnerable position at work and resulting in a reduction in income for some, due to a reluctance to disclose their diagnosis.

Many patients had borrowed money to cover the cost of attendance and some had accumulated debts. In Ethiopia, patients mentioned using savings and selling assets, as previously reported (Cambanis et al. 2005a; Cambanis et al. 2007). In Kenya, the majority of patients had borrowed money and sold assets (most commonly livestock) - generally below the market value – to cover total costs (Mauch et al. 2011). In Yemen, it was difficult to separate the economic impact of diagnostic attendance from that of the illness as a whole. Many Yemeni patients reported a reduction in income from losing a job or having reduced earning capacity due to physical weakness or absence.

#### *Financial barriers and enablers for attendance, Ethiopia and Yemen*

The majority of patients found that the direct and indirect costs of diagnosis and treatment weighed heavily. In Yemen, financial constraints were one of the key reasons given by patients for defaulting from diagnosis, with the expense of private sector tests and medication on referral from the NTI being particularly important. Although patients defaulting from diagnosis were not interviewed in Ethiopia, patients completing diagnosis in both countries found that financial constraints, including concern over loss of earnings due to their absence from home and in Yemen the problem of overnight accommodation, made returning for a second day of the diagnostic process difficult. Patients in Ethiopia were infrequently referred to the private sector, since the health centres provided a service for a wider range of health conditions, but many paid for non TB medication and found the expense unaffordable. Conversely, as might be expected, having sufficient financial means facilitated patient attendance for diagnosis and treatment. Patient attendance was facilitated by receipt of financial support from an employer or relative and secure employment with paid leave for sickness absence. The vast majority of patients however were hindered by financial or work concerns, which caused some to drop out of the process, choose not to collect prescriptions or to pursue a private sector referral. Many patients mentioned having delayed attendance due to financial constraints, as previously reported in this setting (Cambanis et al. 2005a).

### *Factors associated with high patient expenditure*

The factors associated with high costs in Ethiopia and Yemen at univariate level were rural or other town residency, low education, being accompanied and certain occupations (farmer, student, housewife or labourer). In Ethiopia, illness duration of 12 weeks or more and being with a partner or married were also risk factors. The independent risk factors for high patient expenditure on diagnosis across the four study sites were attending the clinic with company and residing in a rural area or other town. Although higher expenditure by patients travelling from elsewhere is logical, it reinforces the need to ensure patients local access, quality diagnostic services and to work to overcome non-financial access barriers to local attendance. Some authors have documented the additional costs incurred by patients' companions and household members. Wyss et al. calculated the direct and indirect costs for companions and household members since disease onset, amongst which the cost of transportation was a major constituent, as did Karki et al., while Kemp et al. reported opportunity costs for household members (Karki et al. 2007; Kemp et al. 2007; Wyss et al. 2001).

It is difficult to find explanations for all of the factors associated with high patient expenditure by performing sub analyses by population characteristic within the relatively small sample size of a qualitative study; nevertheless, low education, certain manual occupations and rural residency were linked to poverty and vulnerability. Long illness duration signifies delayed presentation, which again, is often more common among socially and economically deprived patients with low education. The association of being married or with a partner with the risk of higher expenditure is less obvious, but might relate to the expense of childhood dependants, or the need to make arrangements to leave the household. Since poverty and the cost of attendance are key barriers to attendance at TB services, it is likely that the association lies there.

### *Identifying patients at risk of high expenditure using a score*

The scores developed to identify survey participants at risk of high expenditure are not sufficiently accurate for immediate application, but merit further attention. More work needs to be undertaken to ascertain whether a score should be country-specific or could be applied to a group of countries, or health settings, serving populations with similar demographic profiles. Converting the score to a screening tool that is efficient, non-intrusive and acceptable to patients and health staff, also demands careful consideration. Moreover, the assessment of patients carries validity only if resources are made available to support vulnerable patients. Screening tools have been used in high income countries to assess the poverty status of patients at increased risk of health conditions or complications, with a view to meeting their increased needs. In a study in a primary care setting in Canada, the researchers also took care to assess the acceptability of the questions asked of patients and of the deployment of a tool, during its development (Brcic et al. 2011). In France, a deprivation index (EPICES) has been employed for the same purpose, for example to identify deprived women during pregnancy with a view to reducing maternofetal morbidity (Convers et al. 2011). The index is also widely used in the context of research to explore possible correlations between socio-economic deprivation and disease incidence, severity and outcome (Guize et al. 2008; La Rosa et al. 2008; Nahon et al. 2009), or social conditions such as domestic violence (Sass et al. 2009). In Malawi, Nhlema Simwaka et al. undertook work to develop an assessment tool using local measures of poverty that would provide a socio economic profile of patients accessing the NTP and compared the performance of quantitative and qualitative indicators (Simwaka et al. 2007). The quantitative tool, or proxy means test, was used in a second study to determine patient expenditure on diagnosis in relation to income, with a focus on the relative expenditure of the lowest income group (Kemp et al. 2007) and further evaluations of its application in the field would be useful. The tool to identify patients at risk of high expenditure, described here, would ideally be combined with a means test, since providing additional support to an admittedly small minority of patients that are at risk of high expenditure, but financially well off, would not be an appropriate use of valuable

resources. A means test is of course sensitive to implement as patients are often reluctant to disclose assets. In short, the score has potential as a screening tool to rapidly select patients who may need a more expedited diagnosis, or referral to a support service, but its performance was not as good as desired for a screening tool, as screening requires high sensitivity and would need to be developed further.

#### *Cost savings of an accelerated scheme*

The projected cost of a second day of attendance seems to indicate that introducing the same day diagnostic scheme, as recommended by WHO (WHO 2011a), could make an important contribution to reducing patient outgoings. However services would need to have the infrastructure to provide the test results, offer a final consultation with a clinician, write a prescription, make a referral for anti-TB treatment where appropriate and give health education on the same day. Achievement of the above would necessitate changes to service delivery, with concomitant funding implications.

The larger study in which this thesis was embedded, had envisaged conducting a pilot phase to test these health system changes, however NTP managers were reluctant to change the schemes until the international policy changes had been adopted by the national programmes. Managers hesitated to drop the third smear, consequently most patients had to return the next day to submit a third specimen. As a result, the operation of a frontloaded scheme brought no perceptible advantage to the patient in the current studies and further implementation studies are needed.

Although the costs associated with attendance at formal diagnostic services are not frequently reported, they appear to be considerable as explored through quantitative and qualitative research methodologies and are an important barrier to accessing diagnosis. Schemes to reduce the cost of attendance via government subsidies, or external funding, would improve access by vulnerable populations. Control programmes sometimes provide food supplements, subsidised transport, or abolish clinic fees to encourage treatment adherence (Boccia et al. 2011; Rocha et al. 2011; WHO 2005). Very few programmes to date offer similar support during diagnosis, however, despite

diagnosis being the gateway to free TB treatment. Furthermore, clinic fees should be waived for all patients, whether diagnosed with TB or not. The imposition of fees deters other symptomatic adults from attending. Many patients symptomatic of TB incur costs and all the inconvenience of attendance at TB services, without receiving a clear diagnosis for their illness and receiving a prescription for non TB treatment for which they will be charged. Self-evidently, patients do not know in advance of attending a clinic whether or not they have TB and may not understand the rationale for holding a different charging policy for patients with or without TB, since all patients undergo the same diagnostic testing process. This perceived anomaly could lead to resentment and spread of public mistrust. Of course, finding capital to meet upfront costs in the expectation of making long-term gains can be problematic within a tight national budget and requires considerable national and international commitment. In 2009, leaders of several countries in sub Saharan Africa and Nepal made a series of commitments to increase access to free health services, of which a key initiative was the removal of service user fees for primary healthcare (Campbell et al. 2011). The removal of user fees is generally agreed to be a positive policy initiative to address a counter-productive method of financing healthcare (Campbell et al. 2011; Yates 2009). Nevertheless, some authors advise against a hurried implementation of the scheme, warning of a possible trade-off between improved access and quality of care, within the restricted budget of low income countries (Campbell et al. 2011). There is debate over whether it is possible to abolish user fees for all, or for targeted vulnerable groups alone (Ridde et al. 2011) and some warn of the need for careful preparation before implementing policy reform (Hercot et al. 2011; McPake et al. 2011; Meessen et al. 2011).

### **Non-financial barriers and enablers to attendance**

The cost of attendance is only one albeit a major reason that symptomatic adults find attendance at TB diagnostic services inaccessible. Geographical, social/cultural and health system barriers have also been reported to impede access to TB diagnostic and treatment services (WHO 2005). The principal non-financial barriers to attendance at TB diagnostic services reported by patients in

Ethiopia and Yemen showed many similarities. The key barriers were physical and logistical obstacles, a lack of understanding of the technical aspects of diagnosis, diagnostic duration of longer than one day, the poor attitude of and communication with staff, and the attraction of the private sector. The principal differences between the two countries lay in the particular difficulties identified for female patients in Yemen and patients' fear of the disease and its associated stigma in Ethiopia.

There were fewer similarities between the two countries in the factors which facilitated attendance and completion of diagnosis, beyond the support of family and friends. In Yemen, patients were more likely to complete if they lived near to the health centre and had access to a private vehicle. Some were motivated by a desire to receive a correct diagnosis and be cured, and to protect other family members from illness, which stemmed from the importance they attached to their own health and that of their family. Patients in Ethiopia felt that being well informed about the diagnostic process and its duration, having had a personal recommendation, having had TB before or knowing people that had been diagnosed and treated, and living in the more educated and progressive environment of a city, were supportive factors for attendance. These factors are discussed in the context of the international literature below.

### **Disease history and previous and current health seeking behaviour**

A sizeable proportion of participants in Ethiopia and Yemen (14% and 20% respectively) stated that they had been previously treated for TB. There is, of course, room for error in this self-reported data, since patients' understanding of TB and its diagnosis was shown later to vary. Nevertheless, retreatment is not uncommon due to the difficulty in completing treatment, the emergence of MDR-TB and high HIV prevalence in sub Saharan Africa (Lawn and Zumla 2011; Lonroth et al. 2010a; WHO, 2011b). Over half of Ethiopian patients and the vast majority of Yemeni patients had sought help in other healthcare establishments before attending the study centres, as commonly reported elsewhere (Eastwood and Hill 2004; Gebremariam et al. 2011; Ngangro et al. 2012;

Okeibunor et al. 2006). Since the NTI in Sana'a is a national reference centre, many patients are referred from health establishments across the country and also self-refer, thereby increasing the likelihood of patients having consulted local providers before travelling to Sana'a. It is important to understand why patients, particularly in Yemen, would choose to travel such large distances to major towns and cities for diagnosis and to address these issues. Key reasons include lack of or mistrust of local diagnostic centres, lack of awareness of available services and the strong reputation of referral centres, as discussed later. The majority of patients had consulted private practitioners or other conventional medical services, rather than traditional healers, pharmacists or administering self-treatment, despite the price differential. The preference for private healthcare is widespread in many settings (Khan et al. 2000; Sagbakken et al. 2008b). In this instance it stemmed from a perception that with higher charges comes higher quality, the added convenience of longer opening hours and a faster service. Several patients completing diagnosis in Ethiopia had felt tempted to drop out of the diagnostic process in favour of the private sector and patients in Yemen continued to move between the public and private sectors during and after diagnostic attendance. There was a perception in Yemen that patients with financial means may prefer to seek private healthcare and certainly some defaulters turned to or were referred to the private sector, including in some instances to the private clinics of Centre staff. Many practitioners working in public health services also run private clinics to supplement their income and referral between the two is locally considered legitimate, but can lend itself to abuse if individual profit-making is put before the welfare of the patient. It is also common in many settings for patients to purchase anti-TB medicines in the private sector (WHO, 2011b). This preference differs slightly from other studies which report a tendency to first consult traditional healers, informal providers or spiritual healers, to self-treat or purchase over-the counter medicines (Eastwood and Hill 2004; Gebremariam et al. 2011; Ngangro et al. 2012; Okeibunor et al. 2006) before turning to private medicine (Khan et al. 2000; Sagbakken et al. 2008b) and having recourse to public health services when other options have been exhausted. Prior attendance at other establishments is a known risk factor for diagnostic

delay (Bates et al. 2004b; A. Sanou et al. 2004b; Storla et al. 2008; Yan et al. 2007), as well as the cause of considerable household expenditure and impoverishment (Lonnroth et al. 2007; Ukwaja et al. 2012).

### **Attitudes towards and knowledge of TB**

The studies showed many gaps and contradictions in patients' knowledge of TB and TB services. The majority of patients had heard of TB at the time of attendance, were aware that it could be contracted from a person with TB and that it was treatable. At the same time, patients held many misconceptions about methods of disease transmission, most importantly a belief in disease causation brought about by cold air, as found in studies in Ecuador and Ethiopia (Armijos et al. 2008; Gebremariam et al. 2011). Although seemingly unimportant, this belief has the unfortunate consequence of patients preferring to travel with closed windows on public transport and not to air their houses to avoid draughts, therefore increasing the risk of transmission. Mistaken beliefs in disease transmission via diarrhoea and contact with animals were also widely held, particularly among patients in Yemen. Patient narratives in Ethiopia alluded to a misguided association between TB and perceived immoral behaviour, such as the frequenting of prostitutes. Patients and health staff mentioned the need for spiritual cleansing through holy water and abstinence from sexual intercourse, to ensure recovery. Belief in the onset of TB as a consequence of witchcraft (Banerjee et al. 2000; Okeibunor et al. 2006; Sagbakken et al. 2008b), divine punishment (Baral et al. 2007) or disease transmission through immoral behaviour (Armijos et al. 2008; Baral et al. 2007; Gebremariam et al. 2011; Weiss et al. 2008), have been well documented. It is perhaps important to also draw a distinction between these misconceptions and the likely link between certain unhealthy behaviours, such as excessive alcohol consumption and exposure to tobacco smoke or smoking and increased vulnerability to infection and development of active disease (Lonnroth et al. 2008; Slama et al. 2007). Similarly, there was widespread misunderstanding in Ethiopia about how to avoid infection, as many patients, and reportedly staff, recommended using separate eating or drinking utensils, as previously described in this setting (Cambanis et al. 2005a) and elsewhere (Gilpin et al.

2011), and bed linen (Armijos et al. 2008), instead of increasing ventilation and improving cough hygiene. Similarly, patients were unaware of the period during which they remained infectious following treatment initiation, thereby inflating the risk of social exclusion and its likely duration. Many of these misconceptions were also held by health staff, who used lay concepts to explain the disease and perpetuated popular myths, as found elsewhere in Ethiopia (Sagbakken et al. 2008a). A third of patients in Ethiopia were aware of a link between TB and HIV, in contrast to a small minority in Yemen, where the prevalence of HIV is low.

Not all patients completing the diagnostic process understood the doctor's diagnosis, with a substantial number understanding that they had TB, despite a different diagnosis being recorded in the clinical notes. Of more concern was the small number of patients, mainly in Yemen, that had been diagnosed with TB, but reported having been informed they were free of the disease. The discrepancy between the doctor's diagnosis and the patient's understanding could be attributed to a misunderstanding by the patient and/or to poor staff ability or capacity to communicate clearly. Both of these issues could be addressed through staff training covering techniques such as health staff checking that the patient had understood, use of lay terminology and creating a rapport. Alternatively, the patient may not have wished to disclose their disease status, which is indicative of high levels of perceived stigma and has implications for the accuracy of surveys relying on self-reported data.

Many patients failed to recognise the symptoms of the disease and to understand the importance of early diagnosis and treatment. The studies uncovered a lack of knowledge of available TB services, free TB medication, understanding of the smear microscopy routine and the need for retesting during treatment. Low awareness of the availability and location of TB diagnostic and treatment services has been reported in other studies (Gilpin et al. 2011; Long et al. 2008; Okeibunor et al. 2006). Patients in both settings would have liked more health information to accompany their diagnosis, which puts in context the confusion felt by many over their diagnosis, particularly those

with a diagnosis of “not-TB” or “smear-negative TB” in Ethiopia. Perhaps most surprising, was the low knowledge of some members of the health staff, or their maintenance of two belief systems – modern and traditional medicine.

### *Social stigma and disclosure*

The proportion of survey participants that were not prepared to disclose a diagnosis of TB to others was not trivial (14% in Ethiopia and 17% in Yemen). The majority, however, were prepared to inform a relative. In Yemen, more patients were prepared to inform another relative before their spouse, while in Ethiopia the opposite was the case. A sizeable proportion in Yemen intended to inform a friend, followed by a neighbour - more so than in Ethiopia, but in both countries very few patients intended to inform their employer, work colleagues, religious or community leaders. In Yemen, some patients believed that disclosure would have no negative repercussions and felt a duty to inform others, while others moved to a town or city from the countryside and withheld their disease status at work or school. All of the above suggests a high level of perceived or enacted social stigma among the populations served by the health centres. Considerable social stigma is attached to TB (Cambanis et al. 2005a; Eastwood and Hill 2004; Gebremariam et al. 2011; Liefoghe et al. 1995; Long et al. 2001), although the extent and expressions of stigma may vary between national and local contexts (Somma et al. 2008; Van Rie et al. 2008), as seen here. Ethiopian patients reported a common conflation between TB and HIV, which is likely to have increased enacted stigma (Banerjee et al. 2000; Somma et al. 2008), since in some settings there is a mistaken belief that TB can be sexually transmitted (Somma et al. 2008). This association was, perhaps predictably, not made in the low HIV prevalence setting in Yemen. The choice of whether to inform a spouse or relative may reflect the different family structures in the two countries. Reluctance to inform friends, neighbours, work colleagues and employers reflects a real risk of social rejection or loss of employment, as documented in many settings (Atre et al. 2011; Baral et al. 2007; Gibson et al. 1998; Liefoghe et al. 1995; Somma et al. 2008). Yemeni patients held mixed views about whether or not TB would in principle affect a person’s marriage plans, with some believing

disclosure could lead to the rupture of an engagement or reduced marriage prospects. In studies in India, Pakistan and Malawi, TB has been reported to lead to (or generate fear of) divorce or marital problems, diminished marriage prospects and annulment of an engagement (Atre et al. 2011; Liefoghe et al. 1995; Somma et al. 2008).

Patients in Ethiopia had delayed attendance at diagnostic services out of fear of the negative social consequences of having TB and had considered abandoning the process. Moreover, the prejudice surrounding TB was also reputed to be present among health staff, who marginalised TB suspects and treated them with disrespect. Fear of discrimination was a barrier for treatment registration and many patients on treatment did not disclose their TB status to employers or colleagues at work, a decision which carried complications of its own, since the allocation of medication often conflicted with working hours. Delay in attendance, denial, or failure to register or complete treatment due to perceived or enacted stigma have been widely reported (Baral et al. 2007; N. H. Long et al. 2001; Rubel and Garro 1992).

### **Health system barriers and service satisfaction**

Participants that completed the second day interviews expressed a high level of satisfaction with their experience of diagnostic services, including the attitude of staff and information giving. At the same time, patients expressed that there was little opportunity to ask questions of medical staff and the qualitative studies revealed further aspects of service delivery which had caused patients concern or difficulty. Patients in both settings cited many common obstacles to attendance at TB diagnostic services related to service delivery; most importantly poor communication and attitude of health staff, disorganisation and a rushed service. In Yemen, lack of privacy, poor health hygiene, overcrowding and underhand payments were key obstacles and in Ethiopia marginalisation and discrimination by staff. Many of these barriers have been reported elsewhere. Demands for extra payments, mistreatment and discrimination and poor communication of information by health staff

all combine to erode public trust and confidence and to reduce the acceptability of public health services (Hane et al. 2007; Long et al. 2008; Okeibunor et al. 2006; Sagbakken et al. 2008b).

It is important to give a balanced perspective, however, and highlight that health professionals, laboratory technicians and administrative staff are often operating under a lot of pressure, with low pay, in under-resourced health settings, caring for a high volume of patients of whom the majority have low education and understanding of healthcare and disease.

### **Support and companionship**

Large numbers of patients were accompanied, most frequently by a relative, and in Ethiopia, Nepal and Yemen, accompanied patients constituted the vast majority. The proportion of patients attending with company was higher in Yemen than in Ethiopia, with nearly all (particularly female) patients in Yemen attending with company. In Ethiopia too, the majority of females attending were accompanied. In Yemen, it was common (particularly for women) to come in the company of several companions, with the main companion being a relative other than a spouse and friends, work colleagues or neighbours also being in attendance. Ethiopian patients more commonly attended with one other person, most commonly a spouse. These differences are likely to reflect differing family structures and living arrangements. In Yemen, the paternal or maternal families of a married couple live in the same housing complex and women will attend with a relative who is available, which may be an older female or male relative such as brother-in-law, or uncle. In Ethiopia, although the extended family is important, families in towns may not live on the same site.

Approximately twice as many patients in Yemen reported receiving help in the form of financial support, transportation or food, than their Ethiopian counterparts. Again, patients in Yemen were assisted principally by a relative other than a partner, while Ethiopian patients were assisted most commonly by their partner. In addition to material and financial assistance, Yemeni patients received moral support and encouragement and practical assistance such as childcare or taking over household affairs. Often whole families were involved in supporting the patient's attendance at

diagnostic and treatment services in Yemen, where women were seen to require higher levels of support in view of their perceived dependency and vulnerability. Possible explanations for the higher level of support described by Yemeni patients include religious or cultural values or because patients spent more in real terms compared with patients in other settings. Another possible explanation is that the need for support among Yemenis was greater, given that many were attending services far from home. The information above needs to be interpreted with caution, since there may also be cultural differences in a person's willingness to admit a need for material assistance.

Much of the literature describes the importance of family support during the treatment phase to encourage patient adherence (Sagbakken et al. 2008b) and the consequences of TB for the patients' family. Some studies have begun to consider the financial expenditure or opportunity costs for patients' companions, but these have mainly been reported in relation to pre-treatment costs rather than pertaining to attendance at TB diagnostic services (Karki et al. 2007; Kemp et al. 2007; Wyss et al. 2001). This set of studies suggests that relatives, friends and others play a valuable role in providing psychological, practical, emotional and material support to patients to enable attendance at diagnosis, yet the benefits are offset by an increase in costs. For female patients in societies where women are accorded restricted civil liberties, such as Yemen, the provision of support is also a reflection of the alleged vulnerability of the female sex.

### **Gender**

A majority of Yemeni patients recognised that women faced many difficulties to access healthcare, although patients found it difficult to discuss differential male-female access to healthcare. Men and women in Ethiopia also described the particular difficulties that women faced to attend and complete diagnosis; nevertheless, the access barriers for female patients in Yemen, as described in these studies, appeared to be more severe.

Both Yemeni men and women acknowledged that females lacked autonomy to travel alone to health services, to access household funds, to make decisions about their health, to attend without first asking their husband's permission and had difficulty in leaving caring responsibilities for relatives at home, all of which hindered attendance. A further obstacle to female attendance was the expectation that consultations and examinations should be performed by a female member of staff. There was an acknowledgement that some men accorded less importance to the health of females. When women had negotiated attendance at TB services, however, they seemed to enlist a high level of support. In Ethiopia, women also found it difficult to leave their traditional areas of responsibility at home and often hid their illness from their husbands. These barriers were felt to be more acute in rural areas.

Women are widely reported to face multiple barriers to accessing healthcare in LMIC (Begum et al. 2001; WHO 2004, 2005). Lack of control over household finances, healthcare decisions and autonomy to travel are common (Chard 2009; Liefoghe et al. 1995; Onifade et al. 2010; WHO 2005), particularly in countries in which women have fewer freedoms. Women's health may be accorded less importance (Onifade et al. 2010; WHO 2005), as suggested by some patients in Yemen. Women have been known to conceal their symptoms (Conolly and Nunn 1996), as described by patients in Ethiopia, due to a heightened fear of stigma (WHO 2005), since stigma reportedly has a greater impact on women (Hudelson 1996). These barriers are linked to levels of female education and awareness as well as traditional gender roles and are likely to be more evident in poor and rural areas. Differential gender access was a sensitive subject for discussion in Yemen, where there are well defined religious and moral codes about men and women's conduct and position in society, as indicated by patients' expectation for female patients to be seen by female staff. Further studies are needed to ascertain whether disproportionate numbers of symptomatic females remain undiagnosed in the community.

## **Study limitations**

Despite the richness of information provided by the studies, there are important limitations that need to be considered when interpreting the data, many of which have been discussed in previous chapters. Some relate to issues of research design and others to methodological constraints encountered during implementation of the research protocol. They reflect the limits of the research grants obtained, the joining together of research projects with different funding streams, the timing of the release of funding and normal changes of circumstance to research staff in the research steering group.

### *Methodological constraints*

The inability to recruit and interview patients not completing diagnosis in Ethiopia was a key shortcoming of the qualitative studies, as the researchers considered their views and experiences to be key to understanding the barriers to attendance at TB diagnostic services. Instead of comparing the experiences of the 4 patient subgroups (completing and not completing diagnosis; and registering and not registering for treatment) in Yemen and Ethiopia, therefore, the researchers compared their experiences across the 2 settings. Similarly, it proved not to be possible to test the operation of a same day diagnostic scheme using frontloaded smear microscopy, due to the amount of time it takes to approve and implement international policy changes at regional and district level. The patient experience under the standard and frontloaded schemes was not therefore noticeably different and comparison was not meaningful.

Implementing a generic protocol in Yemen presented the researchers with a range of practical, budgetary, logistical, sociocultural and ethical considerations, many of which were products of the cultural, economic, religious and political environment. Of particular prominence were normative attitudes surrounding the *position of women in society*, which restricted their freedom to work, travel and speak autonomously; *religious sensitivities* influencing the content of interview questions and the organisation of individual and group interviews and a *cultural tendency* to conduct one's

daily affairs with company, which affected travel and attendance at the clinic. Some of these issues were new to the UK researchers and were context specific, while others were more general and might be encountered in other research environments. An example of the latter was the effect of the economic climate, employment and working practices on project operations, manifest in the high staff turnover, short working days and multiple and unstable employment positions.

In addition, there was a high rate of non-attenders in Yemen, especially for FGDs. Patients tended to accept, then not attend. When the driver arrived at the house, the household did not open the door, or said the patient was not home, or the patient said s/he was busy (particularly males). Some asked: 'What do you want?', or: 'What benefit is there for me?'.

Often patients gave the wrong address, or a descriptive address that was unclear (because house numbers, street names are not well developed and there are no maps). In addition, it is not easy to knock on doors and ask local people where a patient lives, as residents are suspicious. To draw a parallel, during public health campaigns patients are sometimes vaccinated in front of the house, as Yemenis may not want to invite in people they do not know. Social workers would sometimes spend several hours looking for a patient's house and then be refused entry.

This contrasted with a low refusal rate for the questionnaire surveys. Possible explanations are that the patients were already in the health centre and the survey seemed to be endorsed by the health staff. The questions were less threatening and did not probe into patient's social status or feelings.

Local research staff hypothesised that since Yemeni people are not accustomed to participating in research, they may be wary. The public might associate form-filling with government institutions. In general, people do not have the expectation that someone is there to try and understand their experiences and make their life easier. The suggestion that someone was interested in improving health services was met with incredulity.

### *Issues of research design*

Information was self-reported by patients, not observed and not checked for reliability of responses.

In the qualitative studies, the accuracy of the translated transcript and interpretation of the information provided could not be checked with the interviewee. Although the information was considered trustworthy, there is always the risk that the patients were trying to respond with information that was perceived to please the enumerator or interviewer. Next, the sampling strategy for the cost study was imposed by the study design of a large clinical trial and contained a risk of selection bias, as participants were recruited consecutively, rather than systematically. Further, although the study sites were selected because they served predominantly poor populations, had a high patient turnover, belonged to the NTP and were set in countries with a high incidence of TB, they inevitably had some inherent differences. Only the Ethiopian site was not located in the capital city and patients are unlikely to have travelled from outside the district to attend the clinic. This may have influenced the patient profile, meaning that patients presented with less complex cases and travelled a shorter distance. Moreover, direct costs incurred by patients were not placed in the context of the family's income to provide a measure of affordability. Instead the proportion of poor among the general population in each country setting was given as a comparator.

The study did not address the particular barriers faced by patients with dual HIV/TB infections and children with symptoms of TB, who are likely to experience more stigma and are more dependent on other people to attend the services. Similarly, the study only interviewed those individuals who in one way or another had managed to reach the services. Given that one third of the estimated new cases occurring in the world never contact diagnostic services, there is undoubtedly a pool of individuals who did not manage to overcome these barriers. These are likely to include those with terminal illnesses who were too weak to travel, those who did not believe the diagnostic services were of good quality, perhaps proportionally more women and those in a precarious economic

position. Whether the barriers preventing these individuals from accessing diagnostic services are the same as for those who attend, remains to be explored.

### **Concluding remarks**

This set of studies demonstrates that attendance at diagnostic services for adults symptomatic of TB is a pivotal moment that can lead to correct diagnosis and eventual treatment, or misdiagnosis, default and a return to the community. It is clear from the harrowing case studies in chapters 6 and 7 that the path to diagnosis is lined with snares, twists and turns, false leads and dead ends. There are multiple opportunities for symptomatic adults to hear erroneous advice, to be persuaded to spend precious resources on ineffective medication, to waste valuable time consulting unqualified practitioners and preparing ineffectual remedies. Poverty in its broadest sense, with its accompanying low access to education and health information, increases patients' exposure to these pitfalls, limits the possibility of patient choice and informed decision-making and reduces the chances of a successful health outcome. As is often the case, in an effort to save money, the poor may spend more in the long term and in some cases, pay the ultimate price. If adults do reach TB diagnostic services, this study illustrates that a further set of barriers awaits.

A range of barriers to attendance and completion of the diagnostic process have been presented here. These have traditionally been placed into four broad categories: economic, geographical, social/cultural and health system (WHO 2005). The most important economic barrier was the considerable cost of attendance, which was particularly significant for patients attending from rural areas or other towns and those attending with company. The principal geographical barriers were logistical constraints: namely, displacement from home and physical weakness. Sociocultural barriers included the particular difficulties women faced to attend and the limited understanding of patients, arising from lack of general and health education. Health system barriers proved to be considerable, in particular: diagnostic duration; poor communication of (sometimes erroneous) health information by staff; unprofessional conduct, including discrimination of TB suspects, financial impropriety, publicly held clinics and inappropriate referrals to the private sector. Lastly,

there was a practice of providing a diagnosis and prescription before completion of smear microscopy, a test which requires several visits and in many cases misses the diagnosis because of its low sensitivity. Issues of particular interest in this study were reports of financial misconduct, the benefits and drawbacks of attending with company, diagnostic duration and making a clinical decision on the first day of attendance; none of which have been widely reported.

There is much literature documenting patient and health system delay and treatment default, but little on the difficulties experienced by patients during diagnosis. The available evidence on barriers and enablers to TB treatment has been obtained using different study designs. Although many of the same barriers are reported, it is rare that the range of barriers is identical from one setting to another, which could arguably be a reflection of the different methodologies employed. However the same is true of this set of studies using similar protocols across study settings. We therefore conclude that the barriers experienced by patients, although they have themes in common, vary according to the national, regional and local context, are mediated by socio-cultural factors and norms, the health services in the setting and the individual circumstances and characteristics of the patients, but are underpinned by a common issue: social and economic deprivation.

Moreover, barriers do not operate and are rarely experienced in isolation. To illustrate this point, an adult with few financial means living in a rural area, is likely to be disadvantaged by the physical distance to attend TB diagnostic services, the lack of transport infrastructure, a shortage of money to cover the cost of transport and clinic fees, low education and literacy which means an increased likelihood of attending with company for moral and practical support such as translation and an increased vulnerability to making the wrong healthcare decisions. The adult may have fewer social resources, such as family or friends living in the vicinity of the clinic with whom to stay overnight or family members able to replace their duties in the house or at work. If working, the adult is unlikely to be working under contract and will not be entitled to or afraid of requesting paid or unpaid sick leave from their employer during their absence. In a rural community, the level of awareness and

understanding of TB will be low and myths and misconceptions about the disease and the consequent possibility of marginalisation will be high. If the adult is a woman, many of these difficulties will be heightened further through increased stigma, lower education and lack of autonomy. Thus, many adults in resource poor settings will experience multiple deprivations, which combine to make attendance at and completion of the diagnostic process fraught with personal risk and difficulty. In addition, the most disadvantaged and vulnerable will have fewer economic, social and emotional reserves to overcome these barriers.

This study indicates that a same day diagnostic scheme would bring about substantial benefits to the patient. The scheme has since been recommended by WHO in settings with EQA and a high laboratory workload (WHO 2011a). The scheme could cut costs for the patient by reducing medical and non medical out-of-pocket expenditure for transportation and subsistence, as well as opportunity costs such as loss of earnings. Further benefits include lessening the inconvenience for patients of being away from work and family and having to make alternative arrangements for care of children and relatives, household duties and overnight accommodation. The latter is important, because despite few patients staying in paid accommodation, their relatives are at considerable risk of infection through their act of hospitality.

Although a same day diagnostic scheme is likely to significantly reduce the burden of diagnostic attendance for the patient, their family and wider social network, it will by no means eliminate it, since many of the costs, logistical constraints, social, cultural, structural impediments and health system barriers will remain and these barriers are likely to be more pronounced for adults failing to seek formal healthcare and remaining in the community. Supporting patients to attend diagnostic centres by material means, through the abolition of clinic fees and the provision of food and transport represents one measure among a raft of measures needed to improve case detection, diagnostic rates and treatment uptake. Broader economic and social support could also be provided to patients to attend, complete diagnosis and register for treatment (Karki et al. 2007; Lemaire and

Casenghi 2010; WHO 2005), particularly the most vulnerable and some advocate a more comprehensive approach towards disease control to address poverty and other social risk factors (Kipp et al. 2011). Another, complementary approach is to bring TB diagnostic services closer to the community, which would improve uptake of services and the burden of disease on poor communities. The ability of vertical programme structures to address these issues, however, is limited, since many of the barriers identified in this survey are generic to other diseases associated with poverty (Bates et al. 2004b, 2004c; Blas and Kurup 2010), therefore a range of health services could be offered within walking distance of patients' houses. Many LMIC are trying to solve this problem by recruiting the support of community health extension workers or volunteers. These range from *Agentes de Saude da Familia* in Brazil to the *Health extension workers* in Nigeria and Ethiopia. Some of these approaches have integrated the provision of TB treatment in the community, have the potential to address many of the barriers discussed here and should be explored (Anonymous 2010d). In summary, efforts to move TB diagnosis into the community by identifying symptomatic individuals, collecting sputum samples and returning results to individual households, should continue in tandem with implementation of the same day diagnostic scheme and implementation studies evaluating this approach are currently being conducted in Ethiopia and Yemen (unpublished).

Healthcare providers have a role to play in reducing stigma (Liefoghe et al. 1995) as a key barrier to attendance, through effective communication of health education (Somma et al. 2008). The distinction between taking reasonable precautions to avoid infection and unjustified social marginalisation or rejection of symptomatic individuals can be ambiguous (Atre et al. 2011) and health professionals need to give clear information and make the distinction for their patients. In addition, health education campaigns are needed to inform the general public that TB is curable (Liefoghe et al. 1995). Traditional approaches to health education may not be sufficient to change health behaviour (Waisbord 2007), but should operate alongside work with user groups and community champions to understand and change local health culture (Rubel and Garro 1992).

New diagnostics are also emerging. *Gene Xpert* has made an important contribution to diagnostics by minimising the number of visits, because it is accepted that a single cartridge has higher sensitivity than smear microscopy (Boehme et al. 2010). However, the test requires a laboratory with stable power supply and well established procurement and is relatively expensive. Although its use is being promoted in LMIC (WHO 2012), it is most likely to be made available at district or referral hospital level and therefore patients will still need to travel and, depending on the timing to release results, arrange overnight accommodation. *Gene Xpert* is therefore not the ultimate solution and a point-of-care test that is instant, accessible and can be carried out at home, is still needed and would have greater potential to increase access to diagnostics, particularly in resource poor areas (Xie et al. 2012).

#### **Recommendations and further research**

Many of the challenges to diagnostic attendance raised by patients are context specific and could be addressed by health centre managers and representatives of local or regional NTPs. Not all carry large resource implications. Others would require more substantial financial commitment or sponsorship. Others are more difficult to address still, since they are concerned with the consequences of social, economic and health inequalities, which require reform of the social and economic structures that created them and political will (Lienhardt et al. 2012; Lönnroth et al. 2010b).

We do not attempt here to make suggestions to effectuate broader social, economic or political change. Based on discussions with staff and patients, however, we recommend exploring the feasibility of introducing the following relatively low-cost and easy steps to improve delivery of TB diagnostic services and make services more responsive to patients' needs, with the appropriate stakeholders in the field:

- Providing accurate, regular and accessible health information about TB and available services at public forums, places of work and schools through patient advocates and community leaders, using locally acceptable media.
- Improving communication between the health professional and the patient, in particular in relation to conveying a diagnosis or other health information, by probing the understanding of the disease and the diagnosis with patients.
- Providing a frequent explanation and written displays of the diagnostic process and waiting times.
- Providing training to address gaps in knowledge and perpetuation of popular myths among health staff.
- Improving staff attitude to reduce stigma and invite questions from the patient.
- Clearly identifying prices for procedures and inviting patients to report requests for additional payments.
- Offering flexibility in clinic opening times to minimise opportunity costs.
- Defining clear policies to regulate requests for tests in private laboratories, or the provision of clear pathways for referral to other government or low cost laboratories.
- Defining clear policies to regulate referral of patients to private clinics or developing mechanisms to incorporate these practitioners into the TB Control Programme activities through public-private partnerships.
- Conducting implementation research to develop patient-centred diagnostic services and complete the diagnosis and treatment decision in a single day.

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## Appendix 1. Table: Country health profile

		Ethiopia	Nepal	Nigeria	Yemen	Global average
<b>Population</b>	Total population (000s) <sup>12</sup>	82 950	29 959	158 423	24 053	
	Urban population (%)	17	19	50	32	50
<b>General health</b>						
<b>Indicators</b>	Life expectancy at birth (years) (M; F; both)x	53; 56; 54	65; 69; 67	53; 54; 54	63; 67; 65	66; 71; 68
	Under 5 mortality rate/1000 live births	106	50	143	77	57
	Under 5 mortality rate/1000 live births (rural; urban) <sup>13</sup>	135; 99*	83; 47**	190; 122††		
<b>Workforce</b>	Physicians/10,000 population <sup>14</sup>	0.2†		4††	3×	
<b>Financing</b>	Total expenditure on health per capita (Intl \$, 2010)	51	66	121	122	
	Total health expenditure (% of GDP)	4.9	5.5	5.1	5.2	
<b>Tuberculosis</b>						
<b>Case notifications, New Cases xx</b>	Smear positive (%)	32	45	56	37	
	Smear negative (%)	34	29	39	22	

<sup>12</sup> Data refers to 2010, unless stated otherwise

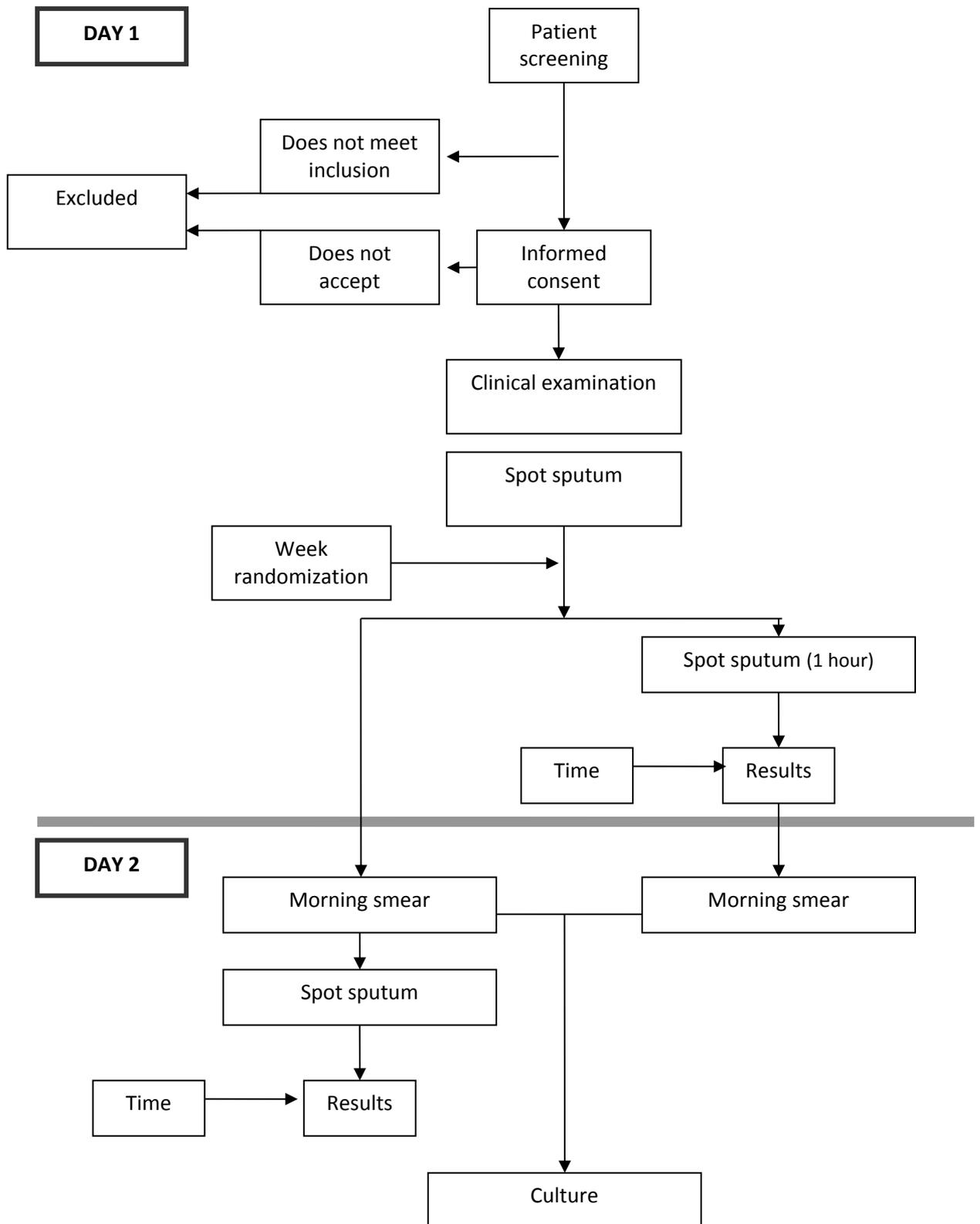
<sup>13</sup> Data source: World Health Statistics, WHO 2012

<sup>14</sup> Data source: Global Health Observatory, WHO 2012

	Smear unknown/not done (%)	2	0	0	7
	Extra pulmonary (%)	32	23	5	34
	Other (%)	0	3	0	0
<b>Treatment success rate</b>	New smear+ and/or culture+	83	90	84	87
	New smear -/EPTB	75	92	77	
	Retreatment	83	85	82	
<b>Laboratories xx</b>	Smear (per 100 000 population)	2.3	1.7	0.8	1.1
	Culture (per 5 million population)	0.1	0.5	0.2	
	National reference laboratory	Yes	No	Yes	Yes
<b>Financing TB Control</b>	Total budget (US\$ millions)	52††	2.6‡	39††	4.6††
	Available funding (US\$ millions)	13††	2.6‡	29††	4.6††
	% domestic funding			30††	13††
	% Global Fund funding	100††	95‡	42††	87††

Data refers to: \* 2005; \*\* 2006; † 2007; †† 2008; × 2009; ×× 2011; ‡ 2012; †† 201

**Appendix 2. Figure: Description of flow of participants for the clinical trial comparing standard and frontloaded smear microscopy schemes**



## Appendix 3. ESRC/DFID protocol

### Identifying barriers to TB diagnosis and treatment under a new rapid diagnostic scheme (Abridged)

"Our greatest concern must always rest with disadvantaged and vulnerable groups. These groups are often hidden, live in remote rural areas or shantytowns and have little political voice." **Dr Margaret Chan, WHO Director-General**

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**Aims and objectives:** The purpose of this study is to identify barriers to Tuberculosis (TB) treatment uptake and strengthen the evidence that accelerated diagnostic schemes lead to increased access to treatment in high incidence countries. The study will, in populations with high TB incidence:

1. Identify barriers preventing adults from completing the diagnostic process for TB when examined through new accelerated schemes
2. Establish whether accelerated schemes for diagnosis results in an increased uptake of TB treatment.
3. Identify changes required by health services to address these barriers

This research will promote equitable and increased access to health services for under-served populations and is key to achieving the Millennium Development Goal of combating HIV/AIDS, malaria and other diseases [including TB] (MDG 6). The study will support a reduction in the prevalence of and death rates associated with TB and increase the proportion of cases detected and cured (health indicator targets 23 and 24) by identifying innovative ways to improve access by poor populations.

Tuberculosis is the main cause of adult death due to infection in developing countries and its diagnosis in these settings requires the examination of multiple sputum samples using smear microscopy. Although smear microscopy was described more than 100 years ago, front line facilities still rely on it as a low cost, relatively simple and robust diagnostic test in the absence of alternatives.

*Despite its widespread use, microscopy has substantial limitations:* it is insensitive, identifying only 40% to 75% of adults with pulmonary tuberculosis and the examination of multiple specimens is costly in time and economic expense for both services and patients<sup>2</sup>. The disease disproportionately affects poor populations in remote areas<sup>3,4</sup> and individuals often have to travel long distances and sell personal assets to access services. Many patients are unaware of the number of days required for diagnosis and, as several visits are necessary, are unable to adhere. As patients can only initiate treatment if they have been formally diagnosed, improving the efficiency of the process is crucial for increasing access to treatment. Improved diagnostic efficiency could be achieved by modifying the way sputum specimens are processed in order to increase the sensitivity of microscopy<sup>5-9</sup>, examining a reduced number of specimens<sup>10-12</sup> and accelerating the collection of samples to within a single day<sup>13</sup>.

*Testing more efficient diagnostic approaches:* Accelerated diagnostic approaches are recognised as a promising way of improving TB diagnosis by the Stop TB Partnership's Task Force on Retooling (<http://www.stoptb.org/retooling>) and are likely to become global policy for TB control in the future<sup>1</sup>. We have designed an accelerated scheme in which specimens are collected one hour apart from each other. This scheme provides test results on the day of consultation and those who tested positive can be referred for treatment within the centre, or elsewhere, within a few hours<sup>13,14</sup>. The approach should be more efficient than the schemes currently recommended by control programmes. Following promising findings in preliminary studies, the WHO/TDR is undertaking a multi-country evaluation, coordinated by LSTM, to validate the scheme and inform both national and international policy.

**Study rationale:** There is an expectation that the accelerated scheme will lead to increased utilisation and effectiveness of services. Yet these improvements may not be significant, as low service uptake is not solely due to economic factors. While it is established that poverty is a significant barrier, other factors such as stigma, popular misconceptions about what causes the disease, gender<sup>15</sup>, perception of service quality and the attitude of health workers play important roles<sup>2, 16, 17</sup>. It is thus necessary to identify and address the non-financial barriers surrounding patients' uptake of diagnosis and treatment when assessed with a new accelerated diagnostic approach and research is needed to ensure that these approaches lead to increased access for the most vulnerable populations.

**Engagement strategy:** A key strategy will be to anchor this research within control programmes, so that knowledge will be rapidly assimilated into policy and practice in partner countries and elsewhere. The WHO/TDR participation will assist control programmes to modify service delivery in response to identified patients' needs. This research will also report its findings at a time when the WHO is reviewing the diagnostic approaches for TB (see for example<sup>5, 18, 19</sup>), with the expectation that new schemes will become operational by 2009. The study therefore is planned in close proximity to working practices and in a position to engage with policy making institutions, ensuring that pro-poor strategies are adopted.

**Study partners:** The study will be led by a Steering Group composed of staff of the Liverpool School of Tropical Medicine and WHO/TDR. Key collaborators are centres that belong to the National Control Programmes in the partner countries of Nepal, Yemen and Ethiopia. These centres belong to countries with high incidence of TB and within DfID priority areas for support.

- LSTM has wide expertise in the successful implementation of research in developing countries. It is a centre of excellence leading innovative research, developing and mainstreaming frameworks for improved understanding of the role and functions of key factors in programming (such as gender, literacy, equity and vulnerability). LSTM research is multidisciplinary, applied and action orientated. Its research on TB is contributing to the development of new diagnostics and approaches for TB<sup>8, 12, 13, 20-22</sup> that are appropriate for disadvantaged populations<sup>2-4, 14, 17, 23-28</sup>.
- WHO/TDR's new research vision "to foster an effective global research effort on infectious diseases of poverty in which disease endemic countries play a pivotal role" is key for this research (<http://www.who.int/tdr/>). TDR uses the expertise of the world's scientific community, selects, guides, funds and develops research and acts as a global facilitator by forming partnerships. Its priorities respond to the Stop TB Partnership's Global Plan (2006–15) call for "strengthening laboratory networks to facilitate detection of all forms of TB" and fosters research into the social and behavioural factors that limit case detection, the assessment of new strategies of case detection and barriers to care<sup>29</sup>.
- The partner in Nepal, Tribhuvan University Teaching Hospital, is a governmental referral hospital for pulmonary diseases. The centre treats approximately 1000 patients with respiratory problems and 200 new TB cases are diagnosed each month.
- The main partner in Ethiopia, Bushullo Major Health Centre, is on the outskirts of Awassa in the Southern Region. This reference district hospital is part of the Regional TB Control Programme and treats approximately 260 patients with chronic cough per month of whom 60 are confirmed to have TB.
- In Yemen, the main partner is the National Tuberculosis Institute in Sana'a. This is a governmental referral centre with approximately 800 patients with respiratory problems and 120 cases of TB attending each month.

Partner co-investigators are well trained; both professionally and for conducting research. The centres were selected because they have a high turnover of patients, many of them from remote rural areas, of whom a high proportion drops out during the diagnostic process. In addition, many of the patients are referred to treatment centres but do not register for treatment.

**General organisation:** The study will be initiated by the Steering Group (LSTM and WHO/TDR), through a workshop for protocol development and will be coordinated by the PI. Each site will have a partner social scientist who will manage a team of social workers and similar activities will be conducted in each. The studies will start in December 2007 for three years, after an initial period of training and standardisation of study procedures.

The research is related to a separately funded multi-centre study to validate the accelerated diagnostic scheme<sup>13</sup>, which will start in September 2007 (see objectives in appendix). This study will be based in Nepal, Yemen and Ethiopia but also Brazil and Nigeria. Patients will be randomised for diagnosis using either the standard or the accelerated schemes. Half of the patients will be examined under the accelerated and half under the standard schemes. The study is expected to enrol 8,000 patients, of whom 1,200 are expected to have positive microscopy over a period of 10 months. Running these studies in tandem therefore will produce synergies by producing in depth critical knowledge about the context of the accelerated diagnostic scheme and help to embed this within the priorities, realities and experience of poor, marginalised and under-served populations.

**Study methods:** The study will use a combination of methods and will be conducted by social scientists and epidemiologists with field assistance from social workers. Multiple methods are particularly appropriate in this context to capture the quantity and meaning necessary for understanding complex human behaviour in different contexts. There is an increasing recognition that triangulating the findings from qualitative and quantitative methods in health research will enable a more thoroughly researched and well understood set of results<sup>30</sup> that is better able 'to negotiate the chaotic environments that are often the stage of public health action'<sup>31</sup>. There has also been recognition that health research that contributes to change may require more methodological pluralism<sup>32</sup> because (1) multiple method approaches that capture both numbers and meaning can be powerful and complementary and (2) different kinds of information resonate with different policy-makers and contexts. The researchers are aware of the stigmas surrounding TB and the sensitivities implicit in the disclosure of TB status and will invite participants in a culturally appropriate manner. The same studies will be conducted with individuals undergoing diagnosis with both the accelerated and the standard schemes.

Quantitative studies will include a combination of data collection from routine surveillance systems and prospective surveys. Routine surveillance data will be examined to monitor withdrawal rates from the diagnostic process, the proportion of patients who initiate treatment and treatment completion rates.

- a. Data on the proportion of patients who do not complete the diagnostic process will be collected from laboratory records of patients using either the standard or the accelerated scheme and will be analysed by age, gender and location, among others.
- b. Patients with a diagnosis of TB are referred to treatment centres. As treatment is not freely available outside these treatment centres, patients need to register to receive treatment. Contact data, including a detailed address for the patient and a relative, land and mobile telephone numbers and the patients' preferred treatment centre will be recorded. Data on the number of patients initiating treatment will be obtained by contacting the treatment centres after the patient is referred. If a patient has not registered within one month of referral, the centres serving the population around the area of residency will be contacted to ascertain if the patient has registered in another centre.
- c. Data on completion of treatment will be obtained from treatment centre records. These will include duration and outcome of treatment.
- d. Cross sectional surveys will be conducted with patients at the time of first attendance for diagnosis to investigate knowledge of diagnostic services and perception of their quality, understanding of the disease, socio-economic background, gender differences and costs incurred. Quantitative data will be analysed using standard statistical methods including summary statistics and confidence intervals.

The characteristics of patients not completing the diagnostic process will be compared with those who complete the diagnosis and the characteristics of patients who register for treatment will be compared with patients not registering. Quantitative studies will be used as a framework to identify participants for complementary qualitative studies.

Qualitative studies will comprise in depth interviews, focus group discussions and case studies to provide an insight into the processes leading to patients abandoning the diagnostic process or treatment at each location. A plan of analysis is included in the appendix.

- e. In depth interviews will be conducted with programme managers to explore operational issues that may hinder patients completing the diagnostic process, potential constraints to modifying services in response to the patients' needs and the financial implications of running a patient centred service.
- f. In depth interviews will be conducted with selected individuals who do not complete the diagnostic process. These individuals will be visited at home, after contacting them by telephone or home visits to arrange appointments. Interviews will aim to confirm the information collected in the initial survey (item d. above) and discuss the reasons why the person abandoned the process. In addition the interview will

explore ways in which services could be modified to facilitate access. Purposive sampling will be used to ensure inclusion of younger and older participants of both sexes, of different socio-economic status and geographical location.

- g. Semi-structured interviews will be conducted with individuals not registering for treatment. Participants will be identified through the surveillance system (item b. above) and will be contacted by phone or home visits. Interviews will be conducted at home or a mutually convenient setting. The same purposive sampling frame as in f. will be used.
- h. Focus group discussions will be conducted with selected participants from groups f and g for methodological triangulation, experience sharing, prioritisation of needs and exploration of group norms and dynamics and their impact on treatment seeking.

In the second year of the study, services in the centres will be modified in response to the research findings. These may take the form of – for example – running diagnostic or treatment clinics after hours, operating an extended X-ray service or improving educational provision. These changes should be funded by the control programmes to ensure sustainability and will be monitored while being piloted, using similar methods to those described above.

**Collaboration arrangements:** There are well established relationships between the partners. LSTM has supported TDR activities over the years, through the provision of technical expert advisors and assistance, training and support of in-country activities and the PI is a member of the TDR DEEP Committee for the development of guidelines on the evaluation of new diagnostics for TB. LSTM staff has also successfully competed for a number of TDR grants related to tuberculosis research and contributed to the development of WHO Guidelines on TB and Poverty. WHO provides financial and technical support for National TB control programmes and the partner centres are collaborating in a multi-country study funded by TDR. LSTM has collaborative links with the Ethiopian centre and the former head of the TB programme in the Region is an LSTM research fellow. LSTM and Bushullo Major have conducted collaborative studies on TB resulting in a large number of peer-reviewed papers<sup>2, 8, 12, 13, 17, 33-36</sup>. LSTM link with Yemen was initiated about 10 years ago through an academic capacity development and training initiative funded by the British Council. More than 15 PhDs and Masters' students have been trained in the last 7 years with continuing support for research and technical activities. Although the LSTM-Nepal link is relatively new, LSTM staff are familiar with research activities in Kathmandu and Prof Sherchand is a PhD graduate from LSTM. Collaborative activities are rapidly increasing since the signing of the peace agreement in 2006.

**Capacity strengthening:** Individual capacity training for research and senior staff from Ethiopia, Nepal and Yemen will include, as required, training on quantitative and qualitative research methods, research management design and analysis, grant preparation, communication skills and ways to influence policy. It is intended to create a network of South-South collaborators exchanging ideas and experiences and that these centres will become regional hubs for research and resources for initiatives in Tuberculosis. Research capacity strengthening, defined as strengthening the capacity for knowledge acquisition and use within developing countries, will aim to improve the flow and democratisation of health system and social science knowledge in the context of TB management. There is a substantial pool of knowledge available through these partners, although this knowledge is not necessarily available on a wider scale, or presented in ways that allow generic lessons to be extracted. Capacity strengthening will therefore take the form of individual and institutional strengthening through shared knowledge. Individual strengthening will be achieved through training, including awareness of excluded patients and barriers for access to treatment, skills in gender and poverty analyses and research skills for programme evaluation. Institutional strengthening will be achieved through the provision of equipment, information access and support to create a critical mass for research and policy advice. In addition to specific individual and institutional strengthening, the creation of a virtual network will support the flow of information to policy makers, facilitate exchange of information, skills and experiences and promote South-South exchanges.

## Appendix 4. PhD scholarship proposal

### Accelerated diagnostic tests for Tuberculosis Lessons to inform International Policy

**Rationale:** Tuberculosis (TB) is a major public health problem with more than 2 million deaths in the world annually. The WHO target for its controls is to diagnose 75% of new cases and to cure 85% by 2015. If these goals were met, TB incidence would decline annually, however meeting these targets has proven difficult with only 53% of cases having been detected in 2004 (Keeler et al. 2006).

The diagnosis of TB requires the examination of sputum through smear microscopy. This method has remained unchanged for more than a century and is a pillar of the global strategy to control, although it has significant limitations. The diagnosis requires the collection and examination of many samples, and because of consequent delays from 2 to 7 days, many people abandon the process and do not return for results (Mase et al. 2007). However other diagnostic methods offer limited benefits for the developing world due to the constraints on their effectiveness and the infrastructure required (Keeler et al. 2006). For example culture of sputum has a much higher sensitivity but requires several weeks to obtain results and an infrastructure that is not widely available in poor areas.

A recent review of the potential global impact of better diagnostic tests for TB (Keeler et al. 2006) highlighted that a key factor to reduce the number of deaths worldwide is to increase the accessibility of diagnostics and to speed up the diagnosis with new or existing methods. Furthermore, although many new diagnostic methods are currently under development, the review describes that to obtain significant gains from new diagnostics would require much better test performance than smear microscopy, and that this is often at the expense of accessibility. Developing accelerated schemes for the diagnosis of TB using existing technologies therefore would potentially result in larger gains (through increased accessibility and lower numbers of individuals abandoning the process) and significant reductions in mortality (through increased diagnosis and treatment uptake) than new methods.

Accelerated diagnostic approaches are recognised as a promising way of improving TB diagnosis by the Stop TB Partnership's Task Force on Retooling and are likely to become global policy for TB control in the future (<http://www.stoptb.org/retooling>). Our research group has designed an accelerated scheme in which specimens are collected one hour apart from each other (Cambanis et al. 2006b; Hirao et al. 2007). The scheme provides test results on the day of consultation and those who tested positive can be referred for treatment within the centre, or elsewhere, within a few hours. The approach should be more efficient than the schemes currently recommended by control programmes and following promising findings in preliminary studies, the WHO/TDR is undertaking a multi-country evaluation, to validate the scheme.

The study assessing the accelerated scheme will be accompanied by parallel studies in Nepal, Yemen and Ethiopia to identify barriers preventing adults from completing the diagnostic process for TB and whether the accelerated schemes result in an increased uptake of treatment. These studies would provide an ideal context for studies leading to a PhD qualification that compares the findings obtained from each country and identify generic lessons to inform international policy, predict the gains that can be expected by the scheme in different scenarios and assess their cost effectiveness.

#### Objectives

The studies conducted by the PhD candidate will therefore aim to

1. Identify barriers to complete the diagnosis of TB and to uptake treatment that are generic to the study settings in order to inform the development of international policies,
2. Calculate the potential gains that would be obtained through the implementation of accelerated schemes in different TB incidence and accessibility of services scenarios.

This PhD study will produce synergies to the national studies proposed in the three countries while representing a discreet piece of academic work. This research will also promote equitable and increased

access to health services for under-served populations and is key to achieving the Millennium Development Goal of combating HIV/AIDS, malaria and other diseases [including TB] (MDG 6).

The candidate will be registered in the University of Liverpool and will be based at the Liverpool School of Tropical Medicine. This is an international centre of excellence for research and training and has more than 100 PhD candidates registered at any one time.

The studies proposed will use a combination of quantitative and qualitative studies and the candidate will be expected to have a background in social sciences. Preference will be given to a candidate with familiarity of developing countries, experience in working in multicultural environments and in qualitative and quantitative research methods. After a period of familiarisation with TB control programmes and international guidelines, the candidate will be expected to spend considerable time supporting data collection by local research teams in Nepal, Ethiopia and Yemen and conducting his/her own studies in the field, followed by a period of data analysis with support from LSTM and WHO/TDR staff.

## Appendix 5. WHO/TDR cost survey questionnaire

### Costs associated with attending the clinic

24	Cost of clinic fees	Number, n digits	
25	Did he/she come alone or with company?	Option	Alone, with company
26	If with company, who accompanied you?	Option	Husband/wife, other relative, friend, neighbour, other
27	Transport used to come to the clinic the first day?	Option	Walked, carried, bicycle, cart/horse, motorbike, bus, car, taxi, other.
28	Time it took to get here from home	Number, 2 digits	Number (hours, minutes),
29	Cost of transport to get to the clinic today?	Number, n digits	
30	Where are you staying overnight?	Option	Home, relative, hotel, street, shift, admitted to hospital
31	Cost of this accommodation	Number, n digits	00 if home or relative
32	How are you coming to the clinic tomorrow?	Option	Walked, carried, bicycle, cart/horse, motorbike, bus, car, taxi, other.
33	Expected transport cost to come to the clinic tomorrow	Number, n digits	
34	How much did you pay for food today?	Number, n digits	
35	Any other expenditure?	Yes, no	
36	If yes, specify		text

## Appendix 6. First and second day interview questionnaires, second survey

### Identifying barriers to TB diagnosis and treatment - DAY ONE

Study site [Ethiopia = 2, Nigeria = 4, Yemen = ]      Date 

d	d	m	m	y	y
---	---	---	---	---	---

Name \_\_\_\_\_ Address \_\_\_\_\_

Mobile phone \_\_\_\_\_ Other phone \_\_\_\_\_

Contact address of next of kin and phone [if different from above]

### General characteristics

Age [If not known enter 99] \_\_\_\_\_ years 

--	--

Sex \_\_\_\_\_ [Male=1, Female=2]

Marital status [Single=1, with partner/married=2, divorced/separated=3, widowed=4]

Mother tongue \_\_\_\_\_

Number of children living at home 

--	--

Residency [Rural=1, same town=2, other town=3]

Can read [Yes=1, no=2, unclear=3]

Education [Nil=1, primary incomplete=2, primary complete=3, secondary=4, tertiary=5]

Currently in paid work [Yes=1, no=2]

Occupation [Farmer=1, student=2, housewife=3, daily labourer=4, merchant=5, government=6, er=7]

If other, specify \_\_\_\_\_

Number of residents in the household 

--	--

Number of rooms [exclude the bathroom] 

--	--

How many people earn money at home? 

--	--

What are their main sources of income? \_\_\_\_\_

Were you born in this country? [Yes=1, No=2]

Specify ethnic, social or tribal group: \_\_\_\_\_

Religion \_\_\_\_\_

Did you come alone or with company? [Alone=1, with company=2]

Relationship of main person accompanying the patient  
[Spouse/partner=1, other relative=2, friend=3, neighbour=4, other=5]

Number of people accompanying the patient

What was the main transport used to come today? [Walked=1, carried=2, bicycle=3, cart/horse=4, motorbike=5, bus=6, car=7, taxi=8, other=9]

Time it took to get here from home?

How long ago did you notice the first symptom of this illness? [not known=99]  
Month  Weeks

Did you seek help elsewhere before coming here? [Yes=1, No=2]

**If yes, where did you go?** [Check whether mentioned or not by the patient]  
**Mentioned?**  
Yes No

Traditional healer/medicine

Pharmacy/over the counter medicine

Self-treated

Primary Health Care [e.g Health centre, health post, health clinic]

Chest (TB) Hospital

Public Hospital Outpatient Clinic

Private Practice (Hospital or Clinic)

Other [specify] \_\_\_\_\_

How many times did you contact other health providers? [Not known=99]

Which health provider did you contact first? \_\_\_\_\_

How long ago? [Months, weeks, days, not known=99] M    ys

**What made you contact this clinic on this occasion?**  
[Check whether mentioned or not by the patient]  
**Mentioned?**  
Yes No

Referred by health provider

Not getting better

No diagnosis

Recommendation/advice

Good reputation

**Did anything stop you from coming to this clinic earlier?** **Mentioned?**

[Check whether mentioned or not by the patient] Yes No

Nothing

Fear of what the doctor tells me

Thought the symptoms would improve

Did not think illness was serious

Fear of social isolation

Lack of money

Clinic is too far

I was too busy

Family/caring responsibilities

Work

Need permission of husband/family

Clinic has a long waiting time

Poor attitude of clinic staff

Poor quality of clinic services

Bad experience on previous visit(s)

Other [specify] \_\_\_\_\_

**The health centre opens from X to X from day to day each week**

How satisfactory are these opening times for you? [Very satisfactory=5, satisfactory=4, neither satisfactory nor unsatisfactory=3, unsatisfactory=2, very unsatisfactory=1, Do not want to say =99]

If these could be changed, what would be your preferred opening times?

From \_\_\_\_\_ to \_\_\_\_\_ From  to   
 [Days] hours min hours  
 min

How long did you wait to be seen by the doctor/nurse today?

[Hours, minutes, not known=99]

So far, are you satisfied with the quality of the service at the centre? [Very satisfactory=5, satisfactory=4, neither satisfactory nor unsatisfactory=3, unsatisfactory=2, very unsatisfactory=1, Do not want to say =99]

How many sputum samples do you need to provide for laboratory tests?  
 [Enter the number stated. If not known=99]

Do you know what disease these tests are for?  
 [TB=1, Other =2, not known=3] [Inform the patient s/he is being tested for TB]

How long do you think it will take to complete the laboratory tests? [Enter 99 if not known]

Days Hours

How long do you think it will take to obtain the results? **Days**

s 

**[Not known=99]**

How much do you expect to pay for your diagnosis at this centre?  
 [Nothing = '00', not known=99]

Have you been treated for TB before? [Yes=1, No=2]

If yes, how long ago? [Months. Not known = 99]

Had you heard of TB before attending this clinic? [Yes=1, No=2]

**If yes, how did you hear about it?**

**Mentioned?**

[Check whether mentioned or not by the patient]

**Yes No**

Radio/Poster/Ministry Of Health campaign

Teacher/community leader

Nurse/health provider

Friends/relatives

Know/know of someone with TB

General knowledge/word of mouth

Social gathering

Don't know

Other [specify] \_\_\_\_\_

**We would like to know what you have heard about TB**

[Ask each question in turn]

Yes No Not known

Is TB inherited? \_\_\_\_\_

Can you catch it from: another person with cough? \_\_\_\_\_

another person with diarrhoea? \_\_\_\_\_

contact with animals? \_\_\_\_\_

evil eye? \_\_\_\_\_

exposure to cold? \_\_\_\_\_

Can people be treated for TB? \_\_\_\_\_

Can TB stop women from having children? \_\_\_\_\_

Can it cause problems for the mother during pregnancy? \_\_\_\_\_

Can it cause problems for the child during pregnancy? \_\_\_\_\_

Does TB stop a mother from breastfeeding? \_\_\_\_\_

Is there any link between TB and HIV? \_\_\_\_\_

Can TB be prevented? \_\_\_\_\_

Do patients pay for TB treatment? \_\_\_\_\_

**If you were diagnosed with TB, would you tell anyone?** [Yes=1, no=2, not known=3]

**If yes, Who would you tell?**

[Check whether mentioned or not by the patient]

**Mentioned?**

Yes No

Spouse/partner \_\_\_\_\_

Other relative \_\_\_\_\_

Friend \_\_\_\_\_

Neighbour \_\_\_\_\_

Work colleague \_\_\_\_\_

Employer \_\_\_\_\_

Religious/community leader \_\_\_\_\_

Other [specify] \_\_\_\_\_

**If patient would not tell anyone, Why not?**

[Check whether mentioned or not by the patient]

**Mentioned?**

Yes No

Fear of being isolated \_\_\_\_\_

Ashamed \_\_\_\_\_

Might lose my job \_\_\_\_\_

Do not want to worry others \_\_\_\_\_

Do not want to take treatment \_\_\_\_\_

Might be asked to leave home \_\_\_\_\_

My partner/spouse might leave me \_\_\_\_\_

Other people would think I have HIV \_\_\_\_\_

Might harm my marriage prospects \_\_\_\_\_

Don't know \_\_\_\_\_

Other [specify] \_\_\_\_\_

Do you think a patient diagnosed with TB would tell others? [Yes=1, no=2, not known=3]

*If yes, Whom would the patient tell?*

*If not, Why wouldn't the patient tell anyone?* \_\_\_\_\_

**If the doctor said you had TB, how would it affect you?**

(for example work, caring responsibilities, income, your family or social situation)?

[Check whether mentioned or not by the patient]

**Mentioned?**

Yes No

Would not affect me \_\_\_\_\_



**very satisfactory to very unsatisfactory.**

For the following questions enter: Very satisfactory=5, satisfactory=4, neither satisfactory nor unsatisfactory=3, unsatisfactory=2, very unsatisfactory=1, Do not want to say =99

Was the waiting time to see a doctor/staff satisfactory to you?

Was the time needed to complete the diagnosis satisfactory to you?

How would you rate the attitude of health staff?

How would you describe the information you received?

Did you feel able to ask questions to doctors/staff? [Yes=1, No=2, Not known=3]

Do you know what disease you have been diagnosed with?  
[TB=1, Others=2, not known=3]. [Inform patient s/he has/has not been diagnosed as having PTB]

If other than TB, specify \_\_\_\_\_

Were you tested for HIV? [Yes=1, No=2, Not known=3]

If tested, could you tell us the result? [Positive=1, negative=2, Not known=3]

**How do you think you got this disease?** **Mentioned?**  
[Check whether mentioned or not by the patient] **Yes** **No**

- I inherited it
- 
- I caught it from someone with TB
- 
- I caught it from someone with cough
- 
- I caught it from someone with diarrhoea
- 
- I caught it from contact with animals
- 
- Evil eye/spell
- 
- Exposure to cold
- 
- I am/might be HIV+
- 
- At a social/market gathering
- 
- On public transport
- 
- Don't know
- 

Other [specify] \_\_\_\_\_

Do you plan to tell anyone that you have been diagnosed with this disease?  
[Yes=1, No=2, Undecided=3]

**If yes, Whom will you inform?** **Mentioned?**

- [Check whether mentioned or not by the patient]
- Spouse/partner
- 
- Other relative
- 
- Friend
- 
- Neighbour
-

-----  
 Work colleague  
 -----  
 Employer  
 -----  
 Religious/community leader  
 -----

Other [specify] \_\_\_\_\_

**What reaction do you think they will have? Mentioned?**

[Check whether mentioned or not by the patient] **Yes      No**

-----  
 Will support/care for me  
 -----  
 Will be concerned about my health  
 -----  
 Will look down on me/reject me  
 -----  
 Will be anxious about catching the disease  
 -----  
 Might ask me to leave home  
 -----  
 My partner/spouse might leave me  
 -----  
 Will think I am HIV+  
 -----  
 Don't know  
 -----

Other [specify] \_\_\_\_\_

**If not, Why won't you inform anyone? Mentioned?**

[Check whether mentioned or not by the patient] **Yes      No**

-----  
 Fear of being isolated  
 -----  
 Ashamed  
 -----  
 Might lose my job  
 -----  
 Do not want to worry them  
 -----  
 Do not want to take treatment  
 -----  
 Might be asked to leave home  
 -----  
 My partner/spouse might leave me  
 -----  
 Will think I am HIV+  
 -----  
 Might harm my marriage prospects  
 -----  
 Don't know  
 -----

Other [specify] \_\_\_\_\_

**Did anybody support you through the diagnostic process and how? [Check]**

	Supported by				
	Financial	Transport	Food	Accompanied	Other [specify]
Partner/spouse					
Friend/neighbour					
Other relative					
Other [specify]					

How difficult was it to complete the diagnostic process?   
 [Very easy=5, Easy=4, Neither easy nor difficult=3, Difficult=2, Very difficult=1]

**What things made it difficult for you to complete the diagnostic process? Mentioned?**

[Check whether mentioned or not by the patient] **Yes      No**

-----  
 Needed permission of husband/family  
 -----  
 Needed someone to accompany me  
 -----

- 
- Distance to health centre prohibitive
- 
- Staying overnight
- 
- Cost of attendance prohibitive
- 
- Caring responsibilities
- 
- Household chores
- 
- Poor access to food
- 
- Physical effort of attending
- 
- Loss of work/income
- 
- Workplace/employer not supportive
- 
- Family/friends not supportive
- 
- Don't know
- 

Other [specify] \_\_\_\_\_

**Clinical management**

Did the patient complete the diagnostic screening for TB? [Yes=1, No=2]

Was the patient diagnosed as having TB? [Yes=1, No=2]

What was decided by the clinician?  
 [Sent for TB treatment in same centre=1, Referred to another centre for TB treatment=2, Referred for further tests elsewhere=3,  
 Continued further tests in the centre=4, Given a course of antibiotics=5, Other=6, Not known=7]

**For TB+ patients only**

Can you tell me what treatment the doctor says you need?  
 [Standard Anti-TB=1, Other antibiotics=2, Other=3, None=4, Not known=5]   
 If other [specify] \_\_\_\_\_

Do you think that the medicines you will receive will cure your illness?  
 [Yes=1, No=2, Not known=3, Other =4]   
 If other [specify] \_\_\_\_\_

For how long will you need to take these medicines? [Not known = 99]

	Years	Months	Weeks
Days	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

**Will you need to take this treatment:**

By mouth? [Yes=1, No=2, Not known=3]   
 By injection? [Yes=1, No=2, Not known=3]   
 Other [specify] \_\_\_\_\_

How often will you need to collect these medicines from the treatment centre?  
 [Monthly=1, Fortnightly=2, Weekly=3, Daily=4, Once only=5, Other=6, Not known=99]

Were you given a choice of places to collect your treatment from?  
 [Yes=1, no=2, unclear=3]   
 Which health facility will you go to? [Name] \_\_\_\_\_

How far is the health facility from your home? [Not known=99] kms    
 How will you get there (main means of transport)?   
 [Walking=1, carried=2, bicycle=3, cart/horse=4, motorbike=5, bus=6, car=7, taxi=8, other=9]

How long will it take you to get there? [Not known=99] Hours  Min

How easy or difficult will it be for you to take the treatment?  
 [Very easy=5, Easy=4, Neither easy nor difficult=3, Difficult=2, Very difficult=1]

*For females*, Do you need the permission of your husband or family to follow treatment? [Yes=1, no=2, unclear =3]

Do you intend to register for treatment? [Yes=1, no=2, undecided=3, not known=4]

Do you intend to seek help elsewhere? [Yes=1, no=2, undecided=3, not known=4]

Do you think it is important to complete the full course of treatment?

[Yes=1, no=2, undecided=3, not known=4]

Will anyone support you through treatment?

[Partner/spouse=1, friend/neighbour=2, other relative=3, other=4, not known=5]

**Thank the patient for his/her time and wish him/her a speedy recovery.**

**Laboratory results (abridged)**

## **Appendix 7. IDI for patients who completed/defaulted diagnosis, registered/not registered for treatment.**

### **PATIENTS WHO COMPLETED DIAGNOSIS (Abridged title)**

#### **Experience of diagnostic services and supportive factors**

**1. How would you describe your experience of diagnostic services at the clinic?**

Prompt: Did you have a positive or negative experience of diagnostic services at the clinic?

Probe: What was positive about your experience?

Probe: What was negative about your experience?

Probe: Please explain.

**2. How do you feel about the standard of the service that you received at the clinic?**

Prompt: What is important for you for service quality? Why?

Prompt: How do you feel about the organisation of diagnostic services?

Probe: Please explain.

Prompt: Was the waiting time to see a doctor/staff acceptable or unacceptable to you?

*If unacceptable*, Probe: Reasons why.

Prompt: Was the waiting time to obtain smear test results acceptable or unacceptable to you?

*If unacceptable*, Probe: Reasons why.

**3. How would you describe the attitude of health staff?**

**4. How do you feel about the information you received?**

Prompt: Did you feel able to ask questions to doctors/staff?

Probe: *If not*, why not?

Prompt: Were there any other issues you would have liked to talk about?

#### **Accessibility of diagnostic services: barriers and enablers**

**5. Did anybody support you through the diagnostic process and how?**

Prompt: What is the person's relationship to you?

Prompt: Did the person support you financially, with transportation, food, accompanying or other?

Prompt: Who was your most important source of support? Why?

Probe: Did anyone else support you through the diagnostic process and how?

Probe: Did you have enough support through the diagnostic process or would you have liked more? Please explain.

**6. How easy or difficult was it for you to complete the diagnostic process?**

Probe: Please explain.

Prompt: After your first day at the centre, how did you feel when you were asked to come back for a second day? [Not for same day smear positive patients].

Prompt: What things helped you to complete the diagnostic process?

Prompt: What things made it difficult for you to complete the diagnostic process?

Prompt: Did anybody make it difficult for you to go through the diagnostic process?

Probe: What is the person's relationship to you?

Probe: How did s/he make it difficult for you?

Prompt: How did it affect your health (access to food, effort of attending)?

Prompt: How did it affect your financial position (cost of attending, opportunity costs)?

Prompt: How did it affect your work (loss of work, loss of income)?

Prompt: How did it affect your family (caring responsibilities, accompanying relatives)?

#### **Suggestions for modifying diagnostic services to facilitate access**

**7. What could have been done by the centre or anyone else to help you to complete the diagnosis?**

Probe: Is there anything else that could have been done?

**8. How do you think diagnostic services could be improved to help patients complete the diagnosis in the future?**

Prompts: Opening times, attitude of staff, standard of care, organisation, clinic costs.

**9. Do you have any other comments to make?**

---

**PATIENTS WHO DEFAULTED FROM DIAGNOSIS (Abridged title)**

**Experience of diagnostic services and reasons for abandoning diagnostic process**

**1. How would you describe your experience of diagnostic services at the clinic?**

Prompt: Did you have a positive or negative experience of diagnostic services at the clinic?

Probe: Please explain.

**2. What prevented you from coming back to the centre to complete the diagnosis?**

Prompt: After your first day at the centre, how did you feel when you were asked to come back for a second day?

Probe: Please explain.

Probe: Were there any other reasons for not coming back to the centre?

**3. How do you feel about the standard of the service that you received at the clinic?**

Prompt: What is important for you for service quality?

Prompt: How do you feel about the organisation of diagnostic services?

Probe: Please explain.

Prompt: Was the waiting time to see a doctor/staff acceptable or unacceptable to you?

*If unacceptable*, Probe: Reasons why.

Prompt: Was the waiting time to obtain smear test results acceptable or unacceptable to you?

*If unacceptable*, Probe: Reasons why.

**4. How would you describe the attitude of health staff?**

**5. How do you feel about the information you received?**

Prompt: Did you feel able to ask questions to doctors/staff?

Probe: *If not*, why not?

Prompt: Were there any other issues you would have liked to talk about?

**Accessibility of diagnostic services: barriers and enablers**

**6. Did anybody support you through the diagnostic process and how?**

Prompt: What is the person's relationship to you?

Prompt: Did the person support you financially, with transportation, food, accompanying or other?

Prompt: Who was your most important source of support?

Probe: Did anyone else support you through the diagnostic process and how?

Probe: Did you have enough support through the diagnostic process or would you have liked more? Please explain.

**7. How easy or difficult was it for you to attend the centre?**

Prompt: How did it affect your health (access to food, effort of attending)?

Prompt: How did it affect your financial position (cost of attending, opportunity costs)?

Prompt: How did it affect your work (loss of work, loss of income)?

Prompt: How did it affect your family (caring responsibilities, accompanying relatives)?

Prompt: What things helped you to attend the centre?

Prompt: What things made it difficult for you to attend the centre?

Prompt: Did anybody make it difficult for you to go through the diagnostic process?

Prompt: What is the person's relationship to you?

Probe: How did s/he make it difficult for you?

### **Suggestions for modifying diagnostic services to facilitate access**

**8. What could have been done by the centre or anyone else to help you to complete the diagnosis?**

Probe: Is there anything else that could have been done?

**9. How do you think diagnostic services could be improved to help patients complete the diagnosis in the future?**

Prompts: Opening times, attitude of staff, standard of care, organisation, clinic costs.

**10. Do you have any other comments to make?**

---

## **PATIENTS REGISTERING FOR TREATMENT (Abridged title)**

### **Attitude to the disease**

**1. Did you tell anyone that you had been diagnosed with tuberculosis?**

*If yes*, Probe: Who did you inform?

Probe: How did they react?

Probe: What stopped you from telling anyone/more people?

**2. Can you tell us the different ways, if any, in which being diagnosed with tuberculosis has affected you?**

Prompt: Has it affected your relationships (partner/spouse, children, work colleagues, friends and family)?

Prompt: Has it affected your work? By work we mean paid or unpaid.

Prompt: Has it affected your opinion of yourself?

Prompt: *If not married*, Has it affected your marriage prospects?

### **Understanding/perception of treatment**

**3. What made you decide to register for treatment?**

**4. Did you discuss your treatment with anybody?**

Prompt: Did anyone influence your decision?

Probe: *If yes*, who?

Probe: *If yes*, What advice did they give you?

**5. Have you looked for help elsewhere?**

Probe: *If yes*, Where?

Probe: *If no*, Do you intend to seek help elsewhere?

### **Accessibility of treatment services: barriers and enablers**

**6. What are the arrangements for your treatment?**

Prompt: Where do you collect your medicines from?

Prompt: How often do you collect them?

Prompt: Do you swallow the tablets at the treatment centre?

Prompt: Does the health worker watch you swallow the tablets?

Probe: *If yes*, how do you feel about that?

Probe: How do you feel about the arrangements for your treatment?

**7. How easy or difficult is it for you to attend the treatment centre?**

Prompt: What things help you to attend the treatment centre?

Prompt: What things make it difficult for you to attend the treatment centre?

Prompt: Do the arrangements for treatment affect your health (access to food, effort of attending)? How?

Prompt: Do the arrangements for treatment affect your financial position (cost of attending, opportunity costs)? How?

Prompt: Do the arrangements for treatment affect your work (loss of work, loss of income)? How?

Prompt: Do the arrangements for treatment affect your family (caring responsibilities, accompanying relatives)? How?

**8. Has anybody supported you to attend the treatment centre and how?**

Prompt: What is the person's relationship to you?

Prompt: Has the person supported you financially, with transportation, food, accompanying or other?

*If yes*, Probe: Is the person still supporting you?

Probe: Has anyone else supported you through the diagnostic process and how?

**9. Who is your most important source of support?**

Probe: Please explain.

**10. How do you travel to the health centre to access treatment?**

Prompt: How long does it take you to get there?

Prompt: How much does it cost to get there?

**Suggestions for modifying services to facilitate access**

**11. What could have been done by the health centre or anyone else to make it easier for you to access treatment?**

**12. How do you think services could be improved to help patients access treatment in the future?**

**13. How do you think diagnostic services could be improved to help patients complete diagnosis in the future?**

**14. Do you have any other comments to make?**

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**PATIENTS FAILING TO REGISTER FOR TREATMENT (Abridged title)**

**Attitude to the disease**

**1. Did you tell anyone that you had been diagnosed with tuberculosis?**

*If yes*, Probe: Who did you inform?

Probe: How did they react?

Probe: What stopped you from telling anyone/more people?

**2. Can you tell us the different ways, if any, in which being diagnosed with tuberculosis has affected you?**

Prompt: Has it affected your relationships (partner/spouse, work colleagues, friends and family)?

Prompt: Has it affected your work? By work we mean paid or unpaid.

Prompt: Has it affected your opinion of yourself?

Prompt: *If not married*, Has it affected your marriage prospects?

**Understanding/perception of treatment**

**3. What stopped you from registering for treatment?**

Probe: Is there a solution to this problem?

**4. Did you discuss your treatment with anybody?**

Prompt: Did anyone influence your decision?

Probe: *If yes*, Who?

Probe: *If yes*, What advice did they give you?

**5. Have you looked for help elsewhere?**

Probe: *If yes*, Where?

Probe: *If no*, Do you intend to seek help elsewhere?

**Accessibility of treatment services: barriers and enablers**

**6. What arrangements were made for your treatment?**

Prompt: Where would you collect your medicines from?

Prompt: How often would you collect them?

Probe: How do you feel about the arrangements for your treatment?

**7. How easy or difficult is it for you to attend the treatment centre?**

Prompt: Did anybody offer to support you to attend the treatment centre? Who? How?

Prompt: What things made it difficult for you to attend the treatment centre?

Prompt: How would the arrangements for treatment affect your health (access to food, effort of attending)?

Prompt: How would the arrangements for treatment affect your financial position (cost of attending, opportunity costs)?

Prompt: How would the arrangements for treatment affect your work (loss of work, loss of income)?

Prompt: How would the arrangements for treatment affect your family (caring responsibilities, accompanying relatives)?

**8. How would you travel to the health centre to access treatment?**

Prompt: How long would it take you to get there?

Prompt: How much would it cost to get there?

**Suggestions for modifying services to facilitate access**

**9. What could have been done by the health centre or anyone else to make it easier for you to access treatment?**

**10. How do you think services could be improved to help patients access treatment in the future?**

**11. How do you think diagnostic services could be improved to help patients complete diagnosis in the future?**

**12. Do you have any other comments to make?**

## **Appendix 8. FGD for patients who completed or defaulted diagnosis, registered or had not registered for treatment**

### **FOCUS GROUP DISCUSSION TOPIC GUIDES**

#### **EXPLORING BARRIERS AND ENABLERS FOR COMPLETING THE DIAGNOSTIC PROCESS, PATIENTS' NEEDS AND IDEAS FOR MODIFYING SERVICES**

**Overall, was your experience of diagnostic services positive or negative?**

Prompt: What were the positive things about your experience at the health centre?

Prompt: What were the negative things about your experience at the health centre?

**How would you describe the attitude of health staff?**

**What are the most important barriers for patients to attend the health centre and complete diagnosis?**

Prompt: Is it more difficult for some sections of the community to attend the health centre than others?

Prompt: Do you think women face any different issues in accessing healthcare from men?

**What are the most important factors that help patients to attend the health centre and complete diagnosis?**

**What or who influenced your choice to attend the health centre and complete diagnosis?**

**Do you think that many people in the community know about tuberculosis?**

Probe: What do they say about it?

**How does having tuberculosis affect people?**

Prompts: their relationships, work, opinion of themselves and *if not married* marriage prospects?

**Do people that have tuberculosis in your community talk openly about the disease or hide it?**

**How could diagnostic services for tuberculosis be improved?**

**What could be done to help people to attend the health centre and complete diagnosis?**

**Would it help if people in the community were given more information about tuberculosis?**

Probe: What sort of information?

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#### **EXPLORING BARRIERS AND ENABLERS FOR COMPLETING THE DIAGNOSTIC PROCESS, PATIENTS' NEEDS AND IDEAS FOR MODIFYING SERVICES**

**Overall, was your experience of diagnostic services positive or negative?**

Prompt: What were the positive things about your experience at the health centre?

Prompt: What were the negative things about your experience at the health centre?

**How would you describe the attitude of health staff?**

**What are the most important barriers for patients to attend the health centre and complete diagnosis?**

Prompt: Is it more difficult for some sections of the community to attend the health centre than others?

Prompt: Do you think women face any different issues in accessing healthcare from men?

**What stopped you from completing diagnosis?**

Probe: Did you seek medical help elsewhere?

**What are the most important factors that help patients to attend the health centre and complete diagnosis?**

**Did anyone influence the health care choices you made?**

**Do you think that many people in the community know about tuberculosis?**

Probe: What do they say about it?

**How does having tuberculosis affect people?**

Prompts: their relationships, work, opinion of themselves and *if not married* marriage prospects?

**Do people that have tuberculosis in your community talk openly about the disease or hide it?**

**How could diagnostic services for tuberculosis be improved?**

**What could be done to help people to attend the health centre and complete diagnosis?**

**Would it help if people in the community were given more information about tuberculosis?**

Probe: What sort of information?

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#### **EXPLORING PATIENT'S PERCEPTION OF TREATMENT ACCESS, IDENTIFYING BARRIERS AND ENABLERS FOR TREATMENT ADHERENCE, PATIENTS' NEEDS AND IDEAS FOR MODIFYING SERVICES**

**What are the most important barriers for patients to register for treatment and attend the treatment centre?**

Prompt: Is it more difficult for some sections of the community to attend the health centre than others?

Prompt: Do you think women face any different issues in accessing healthcare from men?

**What are the most important factors that help patients to register for treatment and attend the treatment centre?**

**How do you feel about the arrangements for treatment?**

Prompt: What are the positive things about the arrangements for treatment?

Prompt: What are the negative things about the arrangements for treatment?

**Overall, is your experience of treatment services positive or negative?**

Prompt: What are the positive things about your experience at the health centre?

Prompt: What are the negative things about your experience at the health centre?

**How easy or difficult is it for you to attend treatment services?**

**How would you describe the attitude of staff at the health centre?**

**Did anyone, or anything, influence your choice to register for treatment or not?**

**Do you think that many people in the community know about tuberculosis?**

Probe: What do they say about it?

**How does having tuberculosis affect people?**

Prompts: their relationships, work, opinion of themselves and *if not married* marriage prospects?

**Do people that have tuberculosis in your community talk openly about the disease or hide it?**

**How could treatment services for tuberculosis be improved?**

**What could be done to help people to attend treatment services and complete treatment?**

**Would it help if people in the community were given more information about tuberculosis?**

Probe: What sort of information?

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**EXPLORING PATIENT'S PERCEPTION OF TREATMENT ACCESS, IDENTIFYING BARRIERS AND ENABLERS FOR TREATMENT ADHERENCE, PATIENTS' NEEDS AND IDEAS FOR MODIFYING SERVICES**

**What are the most important barriers for patients to register for treatment and attend the treatment centre?**

Prompt: Is it more difficult for some sections of the community to attend the health centre than others?

Prompt: Do you think women face any different issues in accessing healthcare from men?

**What are the most important factors that help patients to register for treatment and attend the treatment centre?**

**How do you feel about the arrangements for treatment?**

Prompt: What are the positive things about the arrangements for treatment?

Prompt: What are the negative things about the arrangements for treatment?

**How easy or difficult is it for you to attend treatment services?**

**Did anyone, or anything, influence your choice to register for treatment or not?**

Prompt: what is the reputation of the health staff at the treatment centre?

**Have you sought medical help elsewhere?**

**Do you think that many people in the community know about tuberculosis?**

Probe: What do they say about it?

**How does having tuberculosis affect people?**

Prompts: their relationships, work, opinion of themselves and marriage prospects?

**Do people that have tuberculosis in your community talk openly about the disease or hide it?**

**How could treatment services for tuberculosis be improved?**

**What could be done to help people to attend treatment services and complete treatment?**

**Would it help if people in the community were given more information about tuberculosis?**

Probe: What sort of information?

## Appendix 9. Ethical approval

Dr Luis Cuevas  
Liverpool School of Tropical Medicine  
Pembroke Place  
Liverpool  
L3 5QA



18 August 2008

Dear Dr Cuevas

**Re: Research Protocol (08.49) Identifying barriers to TB diagnosis and treatment under a new rapid diagnostic scheme**

Thank you for your letter dated 1 August 2008 responding to the points raised by the Research Ethics Committee. 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 or for the duration of the grant, renewable annually thereafter. The committee may suspend or withdraw ethical approval at any time if appropriate.

**Approval is conditional upon:**

- Submission of ethical approval from other ethics committees
- Notification of all amendments to the protocols for approval before implementation.
- Notification 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 all severe unexpected adverse events to the Committee
- 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 will result in withdrawal of approval. The Committee would also like to receive copies of the final report once the study is completed.

Yours sincerely

Dr D Laloo  
Chair, Research Ethics Committee

Copy: Dr M Yassin

## Appendix 10. Frequency of cases and controls by country

Variable	Ethiopia N (Col%)		Nepal N (Col%)		Nigeria N (Col%)		Yemen N (Col%)	
	Case	Control	Case	Control	Case	Control	Case	Control
	<b>N= 122</b>	<b>N = 380</b>	<b>N= 148</b>	<b>N = 471</b>	<b>N= 119</b>	<b>N = 378</b>	<b>N= 149</b>	<b>N = 450</b>
Age 50 or more	21 (17.2)	62 (16.3)	66 (44.6)	184 (39.1)	13 (10.9)	27 (7.1)	64 (43.2)	168 (37.3)
Male sex	65 (53.3)	213 (56.1)	103 (69.6)	292 (62.0)	59 (49.6)	182 (48.1)	73 (49)	255 (56.7)
With partner/married	87 (71.3)	213 (56.1)	118 (79.7)	389 (82.6)	62 (52.1)	196 (51.9)	108 (72.5)	317 (70.4)
Residency rural/other town	116 (95.1)	171 (45.0)	91 (61.5)	244 (51.8)	22 (18.5)	67 (17.7)	127 (85.2)	205 (45.6)
Illiterate	77 (63.1)	180 (47.4)	44 (29.9)	93 (20.0)	23 (19.3)	34 (9.1)	98 (65.8)	238 (52.9)
Education nil, primary incomplete, primary complete	111 (91.0)	305 (80.3)	91 (61.5)	248 (52.7)	36 (30.3)	110 (29.1)	132 (88.6)	361 (80.2)
Accompanied	119 (97.5)	254 (66.8)	113 (76.4)	322 (68.8)	64 (53.8)	113 (29.9)	140 (94.0)	369 (82.0)
Smear positive (1 or more + smear)	25 (20.5)	86 (22.8)	27 (18.6)	44 (9.3)	18 (15.4)	67 (18.1)	29 (19.5)	91 (20.4)
Culture positive	34 (27.9)	107 (28.2)	28 (18.9)	45 (9.6)	19 (16.0)	61 (16.1)	35 (23.5)	115 (25.6)
Illness duration 12 weeks or more	42 (34.4)	95 (25.1)	69 (47.3)	202 (43.0)	26 (22.6)	92 (24.8)	36 (25.2)	117 (26.4)
Cough duration 5 to 11 weeks	32 (26.2)	83 (22.1)	37 (25.0)	93 (20.0)	22 (18.8)	62 (16.8)	28 (19.9)	90 (20.4)
Not currently working	70 (57.4)	198 (52.1)	103 (69.6)	314 (66.7)	41 (34.5)	89 (23.5)	115 (77.2)	321 (71.3)
Occupation farmer, student, housewife, labourer	103 (85.1)	228 (60.2)	90 (61.6)	276 (59.1)	35 (29.4)	86 (22.8)	132 (88.6)	347 (77.1)

**Appendix 11. Logistic regression all sites (abridged). The same process was subsequently used for each country**

**Initial variables**

**Unconditional Logistic Regression**

Term	Odds Ratio	95%	C.I.	Coefficient	S. E.	Z-Statistic	P-Value
lr_accompanied (Yes/No)	<u>1.9460</u>	<u>1.4876</u>	<u>2.5455</u>	0.6658	0.1370	4.8584	<u>0.0000</u>
lr_age (Yes/No)	0.9825	0.7589	1.2721	-0.0176	0.1318	-0.1338	<b>0.8936</b>
lr_CanRead (Yes/No)	1.3112	0.9986	1.7216	0.2709	0.1390	1.9496	0.0512
lr_Cough_Weeks (Yes/No)	1.1454	0.8847	1.4830	0.1358	0.1318	1.0301	0.3030
lr_CultureResult (Yes/No)	1.0514	0.8137	1.3586	0.0502	0.1308	0.3836	0.7013
lr_CurrentlyWorking (Yes/No)	0.9248	0.7191	1.1895	-0.0782	0.1284	-0.6087	0.5427
lr_Education (Yes/No)	0.8385	0.6305	1.1153	-0.1761	0.1455	-1.2101	0.2262
lr_FirstSymptom_weeks (Yes/No)	1.0251	0.8131	1.2923	0.0248	0.1182	0.2095	0.8341
lr_MaritalStatus (Yes/No)	0.9518	0.7507	1.2066	-0.0494	0.1211	-0.4085	0.6829
lr_Occupation (Yes/No)	1.1216	0.8594	1.4638	0.1148	0.1359	0.8447	0.3983
lr_residency (Yes/No)	<u>2.3245</u>	<u>1.8584</u>	<u>2.9074</u>	0.8435	0.1142	7.3878	<u>0.0000</u>
lr_sex (Yes/No)	1.1272	0.8961	1.4178	0.1197	0.1170	1.0229	0.3064
<b>CONSTANT</b>	*	*	*	-2.1784	0.1769	-12.3164	<u>0.0000</u>

**Final two iterations**

Term	Odds Ratio	95%	C.I.	Coefficient	S. E.	Z-Statistic	P-Value
<b>lr_accompanied (Yes/No)</b>	<u>2.0679</u>	<u>1.6032</u>	<u>2.6673</u>	0.7265	0.1299	5.5944	<u>0.0000</u>
<b>lr_Education (Yes/No)</b>	0.9185	0.7310	1.1540	-0.0850	0.1165	-0.7301	<b>0.4653</b>
<b>lr_residency (Yes/No)</b>	<u>2.5157</u>	<u>2.0342</u>	<u>3.1112</u>	0.9226	0.1084	8.5102	<u>0.0000</u>
<b>CONSTANT</b>	*	*	*	-2.1054	0.1238	-17.0091	<u>0.0000</u>

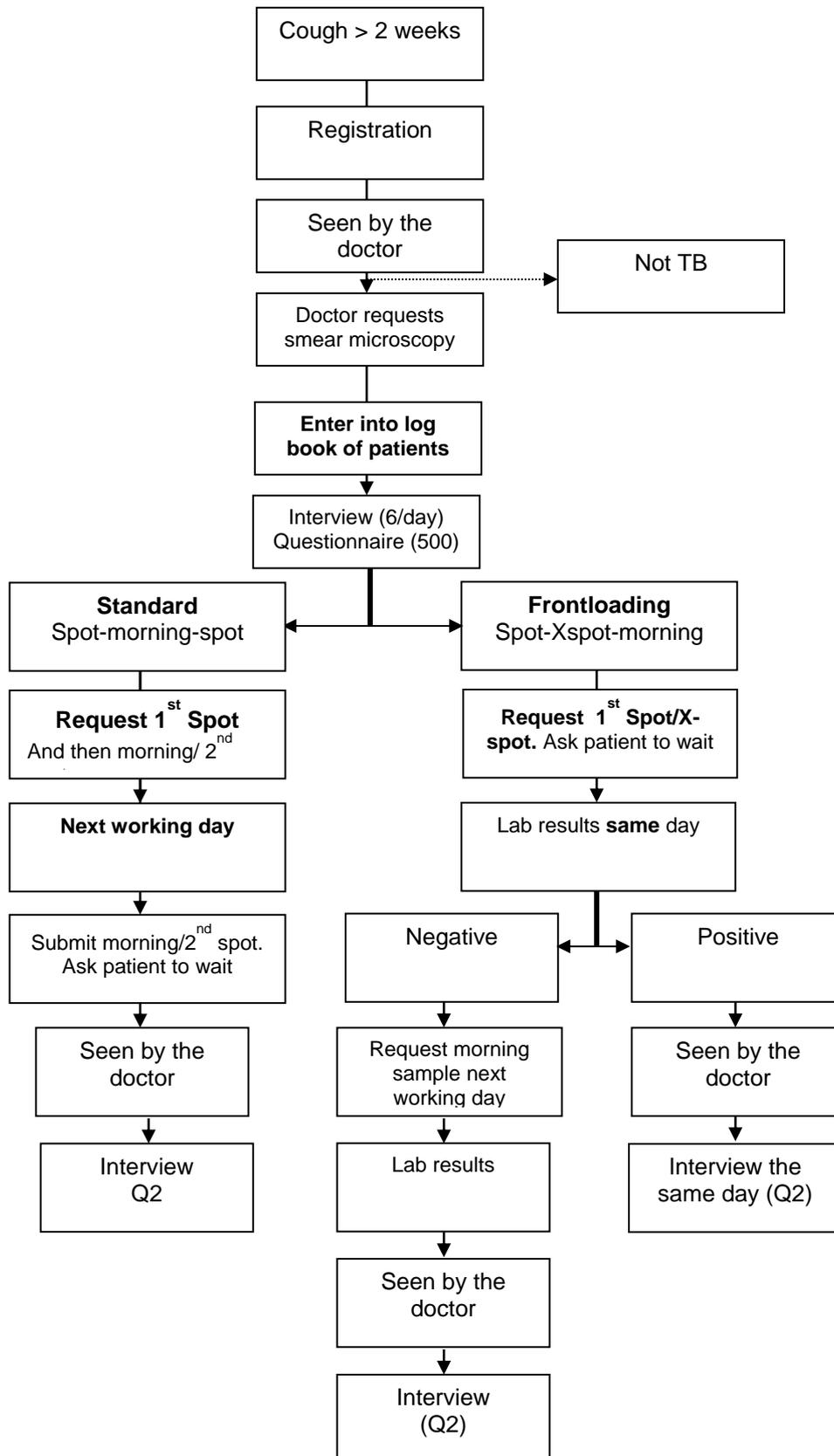
Term	Odds Ratio	95%	C.I.	Coefficient	S. E.	Z-Statistic	P-Value
lr_accompanied (Yes/No)	<u>2.0154</u>	<u>1.5778</u>	<u>2.5743</u>	0.7008	0.1249	5.6112	<u>0.0000</u>
lr_residency (Yes/No)	<u>2.4778</u>	<u>2.0117</u>	<u>3.0519</u>	0.9074	0.1063	8.5341	<u>0.0000</u>
CONSTANT	*	*	*	-2.1335	0.1178	-18.1089	<u>0.0000</u>

Reintroducing excluded variables (selected examples)

Term	Odds Ratio	95%	C.I.	Coefficient	S. E.	Z-Statistic	P-Value
lr_accompanied (Yes/No)	<u>2.0258</u>	<u>1.5808</u>	<u>2.5960</u>	0.7060	0.1265	5.5787	<u>0.0000</u>
lr_residency (Yes/No)	<u>2.4785</u>	<u>2.0108</u>	<u>3.0549</u>	0.9076	0.1067	8.5072	<u>0.0000</u>
lr_age (Yes/No)	0.9628	0.7699	1.2041	-0.0379	0.1141	-0.3322	0.7398
CONSTANT	*	*	*	-2.1280	0.1185	-17.9529	<u>0.0000</u>

Term	Odds Ratio	95%	C.I.	Coefficient	S. E.	Z-Statistic	P-Value
lr_accompanied (Yes/No)	<u>1.9991</u>	<u>1.5614</u>	<u>2.5595</u>	0.6927	0.1261	5.4936	<u>0.0000</u>
lr_residency (Yes/No)	<u>2.4877</u>	<u>2.0130</u>	<u>3.0744</u>	0.9114	0.1080	8.4354	<u>0.0000</u>
lr_FirstSymptom_weeks (Yes/No)	0.9826	0.7905	1.2214	-0.0176	0.1110	-0.1583	0.8742
CONSTANT	*	*	*	-2.1384	0.1223	-17.4847	<u>0.0000</u>

## Appendix 12. Recruitment pathway, survey interview



## Appendix 13. Variables for the logbook

### Day one

Date (separate row at the start of the day)

1. Name
2. Home address and Landmarks for address
3. Patient number
4. Date of registration
5. Age
6. Sex (Male=1; female=2)
7. Mobile phone
8. Mobile or phone number of relative
9. Cough duration (weeks)
10. Scheme (Standard/Frontloading)

### Day two

11. Dropout Day 1 or Day 2? (yes=1/no=2)
12. Smear microscopy (pos=1/neg=2) [Note if positive result given same day]
13. Contacted dropout? (yes=1/no=2)
14. If yes, brief reason for dropping out?
15. If smear positive, centre referred to? [Name of most likely/corresponding centre]
16. Phone number of this centre (if known)
17. Date of 1<sup>st</sup> follow up (two weeks from now)

### Follow up

Health centres/patients phoned/visited? (yes=1/no=2)

Date

Registered? (yes=1/no=2) [if yes enter date registered]

Health centres/patients phoned/visited? (yes=1/no=2)

Date

Registered? (yes=1/no=2) [if yes enter date registered]

If not registered after one month contact the patient and ask for a brief reason why not registered for treatment

Treatment outcome [cured=1, completed =2, died = 3, failure = 4, defaulter = 5, transferred =6]

## Appendix 14. Recording systems, standard and frontloaded schemes

