

To cite this output:

Theobald, S, *et al* (2013) Identifying Barriers to TB Diagnosis and Treatment under a New Rapid Diagnostic Scheme

ESRC End of Award Report, RES-167-25-0387. Swindon: ESRC.



## ESRC End of Award Report

For awards ending on or after 1 November 2009

This End of Award Report should be completed and submitted using the **grant reference** as the email subject, to [reportsofficer@esrc.ac.uk](mailto:reportsofficer@esrc.ac.uk) on or before the due date.

The final instalment of the grant will not be paid until an End of Award Report is completed in full and accepted by ESRC.

Grant holders whose End of Award Report is overdue or incomplete will not be eligible for further ESRC funding until the Report is accepted. We reserve the right to recover a sum of the expenditure incurred on the grant if the End of Award Report is overdue. (Please see the ESRC Research Funding Guide for details.)

Please refer to the Guidance notes when completing this End of Award Report.

<b>Grant Reference</b>	RES-167-25-0387		
<b>Grant Title</b>	Identifying barriers to TB diagnosis and treatment under a new rapid diagnostic scheme		
<b>Grant Start Date</b>	01 May 2008	<b>Total Amount</b>	£237,584.11
<b>Grant End Date</b>	31 Oct 2012	<b>Expended:</b>	
<b>Grant holding Institution</b>	Liverpool School of Tropical Medicine		
<b>Grant Holder</b>	Luis Cuevas and Sally Theobald		
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Mohammed Yassin	Collaborator	Liverpool School of Tropical Medicine**	
Nasher Al-Albahri	Collaborator	National TB Institute, Sana'a	
Jeevan Sherchand	Collaborator	University of Sana'a	
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\*currently retired; \*\* Currently The Global Fund to Fight AIDS, Tuberculosis and Malaria;

\*\*\* currently free-lance consultant.

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## I. Non-technical summary

Please provide below a project summary written in non-technical language. The summary may be used by us to publicise your work and should explain the aims and findings of the project. *[Max 250 words]*

Tuberculosis diagnosis relies on patients attending diagnostic centres and examining several sputum specimens, which requires travel and staying several days near diagnostic centres; reducing accessibility and creating barriers for poor, rural and marginalised populations. Recent diagnostic approaches with potential to reduce the time required for diagnosis were adopted as WHO policies in 2009 and this study aimed to identify barriers to diagnosis and treatment and whether the newly adopted schemes increased access to treatment.

The study took place in Ethiopia, Yemen and Nigeria, locations where patients often abandon the diagnostic process and fail to initiate treatment. Multi-country and multi-stage surveys described the costs incurred accessing tuberculosis diagnostic services, patients' perception of the disease and services and were used to develop models to identify populations at risk of high expenditure. Complementary qualitative methods elicited participants' perceptions of diagnostic and treatment processes, barriers to access services and how services could be modified to improve access.

Accessing services resulted in significant costs, especially clinic fees and transport and among accompanied adults and from rural areas. Most participants (particularly women) attended the services with companions and were unprepared for the duration of the process. Women faced particular difficulties to access services. Patients faced multiple barriers to complete TB diagnosis and the shorter schemes could assist patients by reducing costs, especially if the process is completed in one day. The studies highlighted that access to services is a major barrier and service delivery strategies that identify symptomatic adults at home are currently being evaluated.

## 2. Project overview

### a) Objectives

Please state the aims and objectives of your project as outlined in your proposal to us. *[Max 200 words]*

**Aims and objectives:** The study aimed to identify barriers to tuberculosis diagnosis and treatment uptake and to strengthen the evidence that accelerated diagnostic schemes could lead to increased access to treatment in high incidence countries to inform whether new policies could facilitate diagnosis or inform how services had to be further modified to increase access.

In populations with high TB incidence, the study aimed to:

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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 result in an increased uptake of TB treatment.
3. Identify changes required by health services to address these barriers

A key strategy was to anchor this research within control programmes, so that knowledge could be rapidly assimilated into policy and practice in partner countries and elsewhere. The WHO/TDR participation was intended to assist control programmes to modify service delivery in response to identified patients' needs.

## **b) Project Changes**

Please describe any changes made to the original aims and objectives, and confirm that these were agreed with us. Please also detail any changes to the grant holder's institutional affiliation, project staffing or funding. *[Max 200 words]*

We faced challenges with ethical clearance and change in personnel in Nepal and following consultation with the ESRC did not move forward with work in Nepal, but instead undertook work with partners to document the cost of attending TB diagnostic services in Nigeria. The more limited collection of data in Nigeria comprised similar surveys but not qualitative interviews.

Sally Theobald took over as PI, whilst Luis Cuevas was on secondment to the WHO/TDR, (2009-11). Luis returned to LSTM in Sept 2011 and Sally and Luis continue to work closely together in managing and delivering the planned activities.

We had to make some adaptations to the study in Yemen due to the political crisis, which threatened the security of staff and restricted possibilities to travel and communicate. Field visits from the UK were not possible during 2011 when we had planned to conduct discussions to interpret the information collected. Instead the Yemeni collaborators visited LSTM in February to participate in the analysis and interpretation of data.

All the changes were agreed with the ESRC project officer.

## **c) Methodology**

Please describe the methodology that you employed in the project. Please also note any ethical issues that arose during the course of the work, the effects of this and any action taken. *[Max 500 words]*

We conducted large multi-country and multi-stage cross sectional surveys among adults attending diagnostic centres. The first survey was conducted in Nigeria, Nepal, Ethiopia and Yemen to quantify the cost of attending diagnostic services, describing expenditure for

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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 score was developed by performing logistic regressions of significant risk factors to identify independent variable that could be used to screen 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, to complement information collected using qualitative methods.

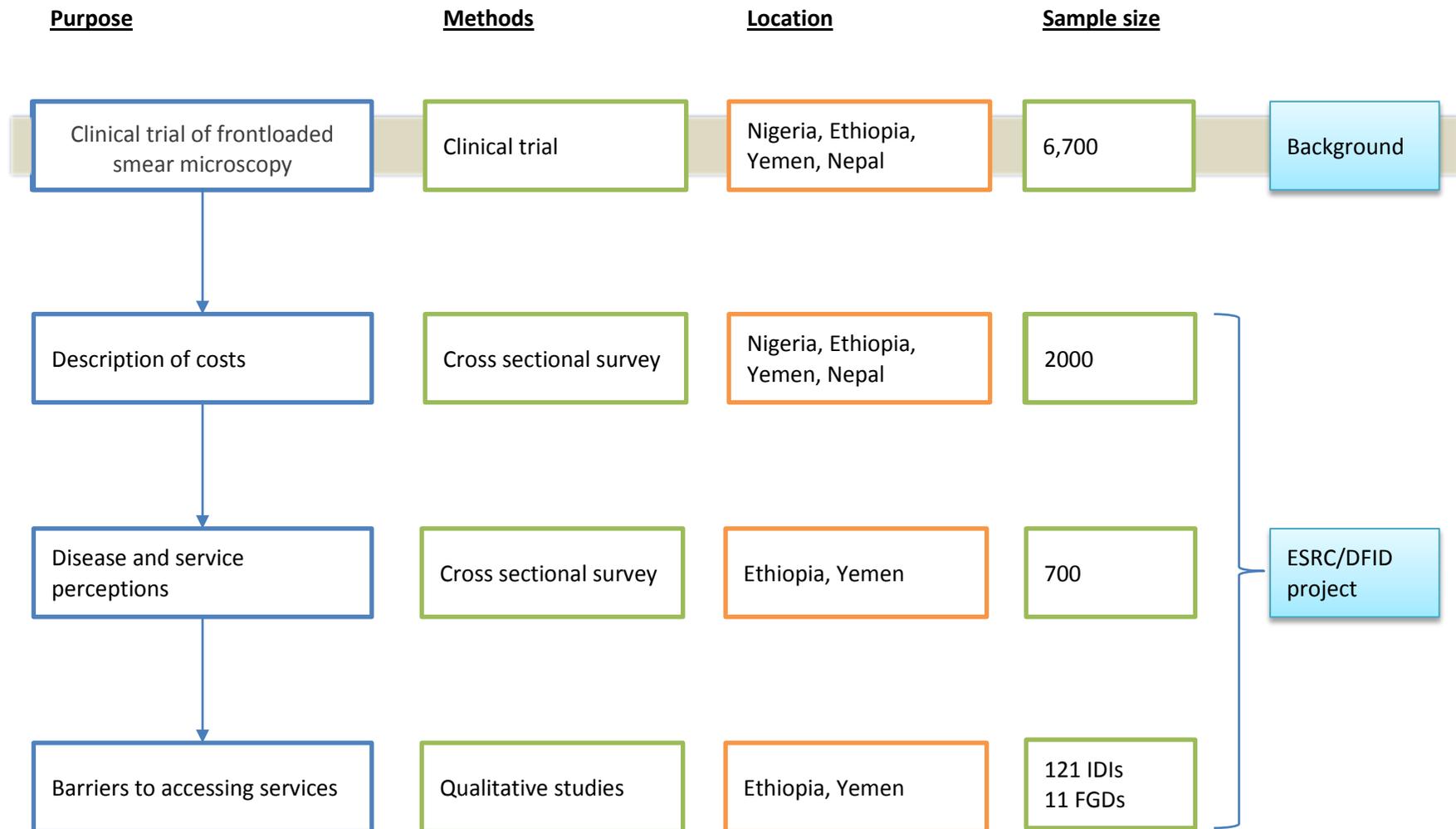
Qualitative studies conducted in Yemen and Ethiopia comprised large numbers of in depth interviews and focus group discussions with individuals who had completed or abandoned the diagnostic process and those who had registered or had decided not register for treatment. Individuals who *completed* the diagnostic process included those with positive and negative smear-microscopy. Interviews also explored ways services could be modified to facilitate access, patients' experiences of the process, and barriers and enablers for diagnostic adherence. Interviews with defaulters aimed to expand on the information collected through surveys to discuss reasons why patients had abandoned the process

Country study coordinators received training in qualitative methods . Interviews were recorded and transcribed in the local languages and translated into English by professional translators. Translations were checked by study coordinators for quality control and re-translated as needed. Field coordinators double translated selected transcripts for comparison with the translator's version to check for accuracy and authenticity. To our knowledge, this is the first qualitative research with tuberculosis patients undertaken in Yemen. Some of the challenges related to political instability, stigma and gender norms and ensuring that women had the freedom to express their views (when they were nearly always accompanied by male relatives).

See Figure I for an overview of the methods and the background studies.

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Figure 1 Diagram outlining the methodological approach



#### **d) Project Findings**

Please summarise the findings of the project, referring where appropriate to outputs recorded on the ESRC website. Any future research plans should also be identified. [Max 500 words]

Costs for attending diagnostic services are significant. The most significant expenses incurred were for clinic fees and transport. Many factors were associated with high expenditure. The main contributors across all 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 across all settings but its performance varied across settings, performing better in Ethiopia and Yemen than in Nepal and Nigeria. The performance of the tool indicate that the approach has potential to screen individuals who may incur high expenditure to attend the services, but that further work is needed to increase the sensitivity to make it suitable for screening. These finding particularly highlight that stationary services at a relatively long distance from the patients' residency are a major obstacle to access TB diagnosis and that bringing the service in proximity to the patient may be as (if not more) important as a shorter diagnostic pathway. Furthermore, most participants (particularly women) attended the services with companions – considerably increasing the cost of diagnosis and patients were often unprepared for the duration of the process. Women were perceived to face particular difficulties to access health services, which is in agreement with surveillance reports that more men are diagnosed to have TB. Patients' reasons for defaulting diagnosis included the cost of the process, receiving negative but incomplete smear results (especially in Yemen) or having a clear chest X-ray on the first day and then receiving misleading or misinterpreting 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 as an important obstacle. In Ethiopia, the lure of attending private sector services and poor staff attitude featured strongly and staff was often perceived as unhelpful.

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. Additionally, or alternatively, diagnostic services could be brought closer to the community. Efforts to bring services closer to communities are currently being explored through additional grants provided by the World Health Organisation (TB REACH) in Ethiopia, Yemen and Nigeria.

### e) Contributions to wider ESRC initiatives (eg Research Programmes or Networks)

If your project was part of a wider ESRC initiative, please describe your contributions to the initiative's objectives and activities and note any effect on your project resulting from participation. [Max. 200 words]

N/A

## 3. Early and anticipated impacts

### a) Summary of Impacts to date

Please summarise any impacts of the project to date, referring where appropriate to associated outputs recorded on the Research Outcomes System (ROS). This should include both scientific impacts (relevant to the academic community) and economic and societal impacts (relevant to broader society). The impact can be relevant to any organisation, community or individual. [Max. 400 words]

Our findings were presented at Global and Regional conferences and in posters and papers. Our team was strategically placed to influence debates in policy and practice in institutions with a leading role in TB policy and practice. Luis Cuevas was seconded to the WHO/TDR and participated in the deliberations to modify diagnostic schemes guidelines. Dr Yassin has a strategic position at the Global Fund, from where he has the opportunity to participate in policy deliberations and influence WHO decisions.

We used the project's and WHO-sponsored studies to engage in policy dialogue and data was incorporated into discussions of evidence for WHO Scientific Advisory Committees. As a result, the Scientific and Technical Advisory Committee of the Stop TB modified its international policies in November 2009 ([http://www.who.int/tb/advisory\\_bodies/stag/en/index.html](http://www.who.int/tb/advisory_bodies/stag/en/index.html)).

Further studies, monitored whether this approach improved treatment uptake and adherence and identified further barriers. In Yemen even with the new approach, the elderly, women and children in Sana'a still had limited access. Data generated informed the development of new initiatives to bring the diagnosis closer to the patient. The team secured further grants from TB REACH (Stop TB Partnership, WHO) to enhance TB case detection (Yemen: Al-Sonboli/Theobald US\$287,621; Ethiopia: 2010 and 2011 Yassin/Theobald US\$689 and US\$654,721; 2013 Cuevas/Datiko US\$ 999,950; Ethiopia and Nigeria: Cuevas/Datiko/Lawson € 845,000 ; Nigeria: Cuevas/Abdurrahman/Lawson US\$ 841,218). These projects address the barriers and costs associated with tuberculosis diagnostics providing an infrastructure to bring services closer to poor and vulnerable groups.

In Ethiopia, the TB REACH project trains village-based Health Extension Workers (HEWs) to facilitate access to diagnosis, reducing travel and time taken to seek diagnosis and

opportunity costs. This approach has doubled TB diagnosis with significant increases amongst women.

In Yemen, the TB REACH project follows contacts of TB patients by visiting households to identify further symptomatic contacts who have not accessed diagnostic services, bringing TB services closer to them. These include the elderly, women and children, as the ESRC/DFID findings had shown these groups faced particular challenges. The project identified that 1 in 10 households had a second person with TB who had not accessed the services.

In Nigeria, HEWs identify adults with symptoms of TB in the slums of Abuja and provide diagnostics for TB and HIV at the point of residence. Again, this approach was informed by the ESRC study and is embedded in the National control programme to secure its ownership and adoption into national policies.

### **b) Anticipated/Potential Future Impacts**

Please outline any anticipated or potential impacts (scientific or economic and societal) that you believe your project might have in future. *[Max. 200 words]*

We will continue to feed our findings into debates in WHO, GFATM, USAID and CIDA and international fora, such as the annual Union TB conference. Our findings have continued to influence the allocation of research funding schemes that aim to increase the identification of cases worldwide.

Currently, we envision potential changes in the national strategies to identify cases of TB in Ethiopia and Nigeria and the team is actively engaging with international funders to highlight the need to bring services to the community. The intensified case finding mechanisms developed are patient-focused and have a highly equitable ethos that follow the principles of primary health care.

You will be asked to complete an ESRC Impact Report 12 months after the end date of your award. The Impact Report will ask for details of any impacts that have arisen since the completion of the End of Award Report.

## 4. Declarations

Please ensure that sections A, B and C below are completed and signed by the appropriate individuals. The End of Award Report will not be accepted unless all sections are signed. Please note hard copies are **not** required; electronic signatures are accepted and should be used.

### A: To be completed by Grant Holder

Please read the following statements. Tick **one** statement under ii) and iii), then sign with an electronic signature at the end of the section (this should be an image of your actual signature).

#### i) The Project

This Report is an accurate overview of the project, its findings and impacts. All co-investigators named in the proposal to ESRC or appointed subsequently have seen and approved the Report.	<input checked="" type="checkbox"/>
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#### ii) Submissions to the Research Outcomes System (ROS)

Output and impact information will be submitted to the Research Outcomes System. Databases are currently being prepared to make them suitable for public access. Details of any future outputs and impacts will be submitted as soon as they become available.	<input checked="" type="checkbox"/>
<b>or</b>	<input type="checkbox"/>
This grant has not yet produced any outputs or impacts. Details of any future outputs and impacts will be submitted to the Research Outcomes System as soon as they become available.	

#### iii) Submission of Data

Data arising from this grant will be offered for deposit with the UK Data Service.	<input checked="" type="checkbox"/>
<b>or</b>	
Data that were anticipated in the grant proposal have not been produced and the UK Data Service has been notified.	<input type="checkbox"/>
<b>or</b>	
No datasets were proposed or produced from this grant.	<input type="checkbox"/>