

End TB in Uganda

Findings of Qualitative Investigation into Pulmonary Tuberculosis in Greater Northern Region of Uganda

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Tuberculosis: Working to Empower the Nations' Diagnostic Efforts (TWENDE)

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1. Introduction and Context

The justification for the University of St. Andrews¹ led *Tuberculosis: Working to Empower the Nations Diagnostic Efforts (TWENDE)* research and advocacy project is an appreciation that huge sums of money and other resources have been invested in developing diagnostic technologies that can rapidly and accurately diagnose pulmonary tuberculosis (PTB), but millions continue to die of PTB every year; among whom are thousands of Ugandans.

As part of the TWENDE Consortium, from January 2016 to December 2017, CPAR Uganda Ltd (CPAR) conducted an in-depth qualitative investigation into PTB in Uganda. CPAR was beneficiary 102332 in the Grant Agreement: CSA-2014-283, between the University Court of the University of St. Andrews and the European & Developing Countries Clinical Trials Partnership (EDCTP) Association to implement TWENDE in Uganda. The EDCTP Association funded TWENDE under its second programme, EDCTP2, funded by the Horizon 2020 European Union Funding for Research and Innovation.

This report is the first in a series of reports for Uganda that CPAR is authoring in order to share its TWENDE findings. In this report CPAR shares its TWENDE findings only for the greater northern region of Uganda. CPAR shall share its TWENDE findings for other regions of Uganda in its other regional reports that it will author. All its TWENDE findings reports, including this one, CPAR will publish as PDF files that can be downloaded from its website www.cparuganda.com.

1.1. The Investigator

Ms. Norah Owaraga², CPAR Managing Director, conducted the CPAR TWENDE qualitative investigation with direct technical supervision from Prof. Christopher Garimoi Orach³, CPAR Board Chair, and with direct administrative supervision from Mr. Alex B. Okello⁴, CPAR Finance Committee Chair.

1.2. Geographic Coverage – The Greater Northern Region of Uganda

The greater northern region, as it is defined by the CPAR TWENDE study, is bordered to the west by the Democratic Republic of Congo, to the north by the Republic of South Sudan and to the east by the Republic of Kenya. The region hosts a population of over 7.2 million people (Uganda Bureau of Statistics 2016) that are residing in 30 of Uganda's 112 administrative districts which existed as of January 2016; of which seven of the 30 districts are located in Karamoja Sub-Region (Abim, Amudat, Kaabong, Kotido, Moroto, Nakapiripirit and Napak); of which eight of the districts are located in Lango Sub-Region (Alebtong, Amolatar, Apac, Dokolo, Kole, Lira, Otuke and Oyam); of which seven of the districts are located in Acholi Sub-Region (Agago, Amuru, Gulu, Kitgum, Lamwo, Nwoya and Pader); and of which eight of the districts are located in West Nile Sub-Region (Adjumani, Arua, Koboko, Maracha, Moyo, Nebbi, Yumbe and Zombo).

¹The University of St. Andrews was the TWENDE Consortium Coordinator under the leadership of Professor Stephen Henry Gillespie, Professor of Medicine; Dr. Ewan Chirnside, Director of Knowledge Transfer Centre; and Dr. Wilber Sabiiti, Senior Research Fellow in Medicine.

²Ms. Norah Owaraga holds a Master of Science Degree in Development Management from the Open University UK and a Bachelor of Arts Degree in Communication Studies from Queen Margaret University, Edinburgh, Scotland, UK. She is a cultural anthropologist and an expert communicator; in which capacities she was among the TWENDE principal investigators; and in which capacities she provided social sciences expertise to the TWENDE consortium.

³Prof. Christopher G. Orach (PhD, MPH, MMed, DPH, MBChB, & Certificate in Health Emergencies) is a medical doctor; a professor of public health and the Deputy Dean of the Makerere University School of Public Health.

⁴Mr. Alex B. Okello (MBA, BSc, DipEdu, DipPA, FCIS) is an administrator who is currently serving in the highest position in the civil service of Uganda; serving as the Permanent Secretary of the Directorate of Ethics and Integrity in the Office of The President of the Republic of Uganda.

1.3. Respondents for the Greater Northern Region

A total of 35 experts (24 men and 11 women) were the direct respondents in the CPAR TWENDE qualitative investigation for the greater northern region; of whom 14 respondents (11 men and 3 women) were interviewed one-on-one; and 21 respondents (13 men and eight women) participated in one focus group discussion (FGD).

The interview respondents were professionals, of whom 57 percent had work experience of 11 years or more. They included: trained teachers, medical doctors, laboratory technicians/technologists, clinical officers and nurses; of whom, at the time of the interviews, 36 percent held political office affiliated to a district local government (DLG) in the greater northern region; 43 percent held office in the Uganda civil service and were deployed to work with a DLG in the greater northern region; and 21 percent worked with the private and the not-for-profit sectors operating in the greater northern region.

The interview respondents had a combined experience of working and living in 15 districts of Uganda; of which nine of the districts are located in the greater northern region, including: two of the seven districts of Karamoja; two of the eight districts of Lango; four of the seven districts of Acholi; and one of the eight districts of West Nile.

Respondents in the FGD were residents of one village in one district within one of the sub-regions of the greater northern region. They included persons who self-identified as social workers, teachers, students, farmers, housewives, drivers and village health team members. Among the FGD respondents were the village political leaders, including the chairman of the village local council.

1.4. Data Analysis Methodology

Recordings of interviews and of the FGD were transcribed into text - direct copies of the recordings in their entirety were manually typed into a computer using Microsoft Word. Using the same software, the Investigator manually 'manipulated' the text – she categorised and coded it.

Categorisation and coding used an inductive approach that allowed the Investigator to gain insights and understanding from the data. The Investigator had no pre-defined rigid coding categories, the coding categories emerged from the qualitative data as it was analysed. Descriptive and interpretative coding of each transcript was done and a theory was built.

As the qualitative data was categorised and coded, decisions were made on how the data could be interpreted. Basically, proxy indicators were derived from the data. The Investigator's proposition is that the derived proxy indicators are useful and valid in determining knowledge, beliefs, perceptions, attitudes, and practices of the respondents and by extension of those whom the respondents talked about and represented. The premise of the Investigator's theory is that the derived proxy indicators legitimise the CPAR TWENDE data as a valid basis on which to draw conclusions on PTB in the greater northern region.

Twelve sets of proxy indicators thought to be useful guides to understanding PTB in the greater northern region were derived from the data as follows:

- PTB prevalence
- Infectious nature of PTB
- Symptoms of PTB
- PTB suspicion index
- PTB diagnostic tests
- GeneXpert machines
- Other PTB diagnostic machines
- PTB treatment drugs
- Adhering to PTB treatment
- PTB care personnel
- PTB patient costs
- Financing PTB care

The 12 sets of proxy indicators were further enriched through statistical analysis using a Microsoft Excel spreadsheet that generated statistical data that allowed the Investigator to establish which topics and issues were discussed by each interview respondent and also by the FGD.

2. Findings for the Greater Northern Region

The CPAR TWENDE findings shared in this report simply and objectively reveal what was discussed during its investigation into PTB in the greater northern region and the percentage of the respondents who discussed each aspect. The use of percentages in presenting the findings in this report only indicates the proportion of respondents who discussed or mentioned particular aspects.

2.1. Prevalence of PTB

During conversations with the Investigator, all interview respondents discussed aspects which can be used to deduce and estimate prevalence of PTB in the greater northern region. The table that follows summarises the aspects that came up during the conversations with regard to PTB prevalence.

PTB prevalence proxies	%
Infected with PTB	100
PTB patients on treatment	93
Co-infected with PTB and HIV/AIDS	86
Infected with MDR PTB	43
PTB among refugees	14

All interview respondents shared views on people infected with PTB; 93 percent shared views on PTB patients on treatment; 86 percent shared views on people co-infected with PTB and HIV/AIDS; 43 percent shared views on people infected with multi-drug resistant (MDR) PTB and 14 percent of them shared views on PTB among refugees.

Views on people infected with PTB; PTB patients on treatment; and people co-infected with PTB and HIV/AIDS came up in the FGD, as well.

2.2. Know PTB

Two sets of proxy indicators emerged which can be used to deduce the respondents' knowledge of PTB and the knowledge of PTB of those that the respondents talked about and represented; they are: the infectious nature of PTB and PTB symptoms.

2.2.1. Infectious nature of PTB

Of the interview respondents, 79 percent discussed aspects which may be used to gauge the depth of knowledge of PTB of the respondents and of those that the respondents spoke about and represented. The following table summarises the emerging proxies for decoding knowledge of the infectious nature of PTB.

Proxies for infectious nature of PTB	%
Fear to be infected	82
Patient quarantine	64
Personal protection	36
TB wards or isolation units	27

Fear to be infected with PTB was discussed by 82 percent of the interview respondents who discussed proxies for the infectious nature of PTB; PTB patient quarantine by 64 percent of them; personal protection from TB by 36 percent of them and TB wards or isolation units by 27 percent of them.

During the FGD as well the following aspects on the infectious nature of PTB came up: fear to be infected with PTB; personal protection from getting infected with PTB; and PTB patient quarantine.

2.2.2. PTB symptoms

During the one-on-one interviews, 86 percent of the interview respondents specifically mentioned what they and the people they spoke about and that they represent know to be PTB symptoms. The following table presents the symptoms that were specifically mentioned and by what percentage of the respondents:

PTB symptoms	%
Cough	92
Weight loss	42
Chest pain	25
General body weakness	25
Loss of appetite	17
Fever or sweating at night	17
Spitting pus	08
Headache	08

Among those which the interview respondents thought to be PTB symptoms, the symptom that was mentioned by the majority of respondents who mention symptoms, 92 percent of them, was cough; weight loss was the next most mentioned by 42 percent of the respondents; followed by both chest pain and general body weakness which were each mentioned by 25 percent of the respondents; followed by loss of appetite and fever or sweating at night which were each mentioned by 17 percent of the respondents; and lastly spitting pus and headache which were each mentioned by eight percent of the respondents.

Of the presumed PTB symptoms that were mentioned during one-on-one interviews, only two of them: cough and general body weakness were also specifically mentioned by the focus group during the FGD.

2.3. Attitude towards PTB Diagnostic Services

A set of proxies emerged from the data which can be used to gauge the PTB suspicion indices of the respondents, of those the respondents spoke about and represented. The proxies for index of suspicion of PTB were those aspects which indicate the likelihood that an individual will make a decision to seek PTB diagnostic services or to advise another to do so; and at what stage they decide to seek or to ask another to seek. Sixty four percent of the interview respondents discussed proxies that can be used to build a qualitative PTB suspicion index. The summary of the aspects and the percentage of the respondents who discussed them are contained in the table that follows.

Qualitative PTB suspicion index proxies	%
Patients's decision to seek medical TB tests	100
Use of 'home remedies' (herbs and procedures)	22
Self-Medication	22
Medical personnel's decision to test patients for TB	11

All of the respondents who discussed aspects that can be used to build a qualitative PTB suspicion index, discussed the decisions by patients to seek medical PTB tests; 22 percent discussed the use of ‘home remedies’; 22 percent discussed self-medication; and 11percent discussed decisions by medical personnel to test patients for PTB.

During the FGD, the matter of patients’ decisions to seek medical PTB tests did come up as well, but the other aspects that were discussed in regard to a qualitative PTB suspicion index did not come up during the FGD.

2.4. Capacity to Diagnose PTB

The data revealed two sets of proxy indicators that one could use to deduce capacity to diagnose PTB. The two sets are: PTB diagnostic tests performed and PTB diagnostic machines used.

2.4.1. PTB diagnostic tests

Fifty percent of the interview respondents during their one-on-one conversations with the Investigator specifically mentioned what in their knowledge they considered PTB diagnostic tests. The table that follows presents the PTB diagnostic tests that were specifically mentioned, in the words that they were mentioned and the proportion of the 50 percent of interview respondents that mentioned them.

PTB diagnostic tests	%
Microbiology or sputum culture	86
X-ray or chest x-ray	57
Bacteriology or ZN (Ziehl-Neelsen)	43
Chest surgery	14

PTB diagnostic tests that were mentioned were microbiology or sputum culture by 86 percent of the respondents who mentioned PTB diagnostic tests; x-ray or chest x-ray by 57 percent of them; bacteriology or ZN by 43 percent of them; and chest surgery by 14 percent of them.

There was no specific mention of PTB diagnostic tests during the FGD.

2.4.2. PTB diagnostic machines

TWENDE has special interest in identifying and examining the barriers to wider up-take of the World Health Organisation’s approved Xpert MTB/Rif (GeneXpert) and Line Probe assays for rapid detection of PTB and drug resistance.

GeneXpert Machines: The CPAR investigation explored up-take and utilisation of the GeneXpert machine and in the one-on-one conversations with 50 percent of the interview respondents GeneXpert machines were discussed. Here below is a table indicating the proxy indicators for examining up-take and utilisation of GeneXpert machines that emerged from the data and the proportion of respondents who discussed each specific proxy indicator.

GeneXpert machine proxies	%
Availability	100
Downtime	86
Supplies	57
Capacity	57
Performance	57
Servicing	43

All of the interview respondents who discussed PTB diagnostic machines discussed availability of GeneXpert machines; 86 percent of them discussed GeneXpert machine downtime; 57 percent of them discussed GeneXpert machine supplies; 57 percent of them discussed GeneXpert machine capacity; 57 percent of them discussed GeneXpert machine performance; and 43 percent of them discussed GeneXpert machine servicing.

Line Probe Assay: PTB diagnostic machines other than the GeneXpert were discussed by 21 percent of the interview respondents and the Line Probe Assay was discussed by 33 percent of them. Of those who discussed diagnostic machines other than the GeneXpert, 33 percent of them discussed the microscope as well.

X-Ray Machines: Of the 21 percent of the interview respondents who discussed other PTB diagnostic machines, 67 percent of them discussed the x-ray machine.

There were no specific discussions of PTB diagnostic machines during the FGD.

2.5. Capacity to Treat PTB

The proxy indicators for the capacity to treat PTB which emerged from the data included proxies for the drugs for treating PTB; and those for the ability of patients to adhere to and to complete PTB treatment. This particular set of proxies was discussed by 93 percent of the interview respondents. A table follows which lists the proxies and which shows the proportion of the 93 percent who discussed each proxy.

PTB treatment proxies	%
Availability	85
Food for patients	54
Social support to patients	54
Manner of administering	46
Economic status of patients	38
Accessibility	31
Side effects	15

Of the 93 percent who discussed proxies for the capacity to treat PTB, 85 percent discussed availability of drugs; 54 percent discussed food for patients; 54 percent discussed social support to patients; 46 percent discussed the manner in which drugs are administered; 38 percent discussed the economic status of patients; 31 percent discussed the accessibility of drugs; and 15 percent discussed the side effects of the drugs.

Except for the side effects of the drugs, all of the other proxies for the capacity to treat PTB that were discussed during the one-on-one interviews came up in the FGD as well.

2.6. Human Resources Deployed to Provide PTB Care

Emerging from the data as a determinant of the capacity to diagnose and treat PTB and therefore to control or eliminate the disease are the human resources that are specifically deployed to provide PTB care. Aspects related to PTB human resources came up in discussion during one-on-one interviews with 71 percent of the interview respondents. The aspects that were discussed are presented in the table below; a table which also indicates the proportion of those among the 71 percent who discussed each proxy.

PTB human resources proxies	%
Deployment	90
Training	90
Remuneration	40

Of those who discussed PTB human resources, 90 percent discussed aspects related to the deployment of the human resources; 90 percent discussed aspects related to the training of the human resources; and 40 percent discussed aspects related to the remuneration of the human resources.

All of the three aspects related to PTB human resources that were discussed during the one-on-one interviews also came up and were discussed by the focus group.

2.7. Financing PTB Care

TWENDE has an interest in aspects related to the financing of PTB care, in particular TWENDE's desire to contribute valuable knowledge on how financing for PTB care could be utilised to generate positive impact. The CPAR TWENDE study explored issues to do with financing of PTB care and two major sets of proxy indicators have emerged from the CPAR TWENDE data: financial costs that are borne by PTB patients and financial costs covered through public service provision.

2.7.1. PTB care financial costs borne by patients

Sixty four percent of the interview respondents discussed aspects related to the costs that are borne by PTB patients. The table that follows presents the proxies for PTB patient care costs and the proportion of the 64 percent of the interview respondents that discussed each of the proxies.

Proxies for PTB care costs borne by patients	%
Transport	67
Diagnostic tests	56
Food	56
Attendants	44

The cost of patients' transport in relation to PTB care was discussed by 67 percent of the interview respondents who discussed PTB costs borne by patients; 56 percent of them discussed patients' costs for diagnostic tests; 56 percent of them discussed costs related to food for patients; and 44 percent of them discussed costs related to attendants helping to care for patients.

During the FGD two of the proxies related to costs borne by patients that are related to PTB care came up and were discussed as well - transport and diagnostic tests.

2.7.2. Public financing for PTB care

All interview respondents made mention of public financing of PTB care. The focus group as well made mention of public financing of PTB care. Public financing for PTB care was particularly discussed in relation to the services provided through public hospitals.

In discussing public financing for PTB care, 29 percent of the interview respondents specifically mentioned external grant funding that according to them is provided for public financing of PTB care. The external grant funding sources that were mentioned are programmes supported by the United States Government through its United States Agency for International Development (USAID) and its Centres for Disease Control and Prevention (CDC) as follows:

- USAID Strengthening Uganda's Systems for Treating AIDS Nationally (SUSTAIN)
- USAID Applying Science to Strengthen and Improve Systems (ASSIST)
- USAID Management Sciences for Health Track Tuberculosis (MSH TRACK TB)
- CDC in Uganda

3. Conclusion and Next Steps

The findings in this report are based on the first level analysis of the CPAR TWENDE qualitative data set for the greater northern region. The first level analysis focused the data; simplified it and organised it in a manner that allowed a bottom-up analytical framework to emerge.

CPAR plans to utilise the analytical framework that has emerged as a guide to further in-depth analysis of its TWENDE qualitative data set in order to derive from the data specific opinions and conclusions on prevalence of PTB and PTB management in the greater northern region.

It is important to emphasise that the percentages used in this report **DO NOT** attach values to the data; values, for example, that could be used to do ranking or to prioritise. Consequently, the findings in this report do not reveal the depth or breadth of the discussions that were held during the investigation; nor do they reveal the opinions of the respondents or the opinions of the Investigator.

Further analysis of the data is being done and more detailed analyses will be generated that will reveal the breadth and the depth of the discussions; and the opinions of the respondents and the Investigator. CPAR will share the more detailed analyses in the form of briefs and opinions; and in the form of articles for publication in academic journals.

4. About the Author

Ms. Norah Owaraga authored this report on behalf of CPAR.

Ms. Owaraga's professional experience spans since 1992, during which time she has worked as a senior executive in civil society organisations; currently as the CPAR Managing Director since April 2012.

Her work experience includes that which she has gained through doing consultancies. Among others, she has consulted with government departments, civil society organisations and the business sector, providing her expertise on human centred policy development; on programmes implementation; on social accountability; on civic education; on wealth creation; on poverty reduction; on land justice; and on healthcare services provision; and other areas.

As an active citizen, she is a humanist who regularly shares her opinions on a wide range of issues through her blog, "*The Humanist View*" on Wordpress; and through social media. Since January 2017, she is the first and to date (June 2018) the only female political radio talk show host in Uganda, hosting the prime time weekly show: "*Spectrum Extra*" on Radio One FM90 that is broadcast live on Friday evenings 7-9 pm. *Spectrum Extra* provides Ms. Owaraga with a platform through which she interacts with a varied range of views and through which she holds leaders in Uganda to account.

She is a Fellow of the African Leadership Initiative East Africa (ALI EA) and a member of the Aspen Global Leadership Network (AGLN).

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