# CPAR UGANDA LTD

***a not-for-profit company limited by guarantee and is without share capital***

**ADVOCATING FOR HEALTHY DIGNIFIED LIVES**

# Discussion of Research Findings on Prevalence of Pulmonary Tuberculosis in Greater Northern Uganda



## Contact Us:

Plot 5 Makerere Road, Lira Municipality
P.O. Box 820, Lira
Email: info@cparuganda.com

## Introduction

The Ministry of Health (2015), estimates Uganda's national tuberculosis (TB) prevalence rate at 253/100,000; an estimated 87,000 TB cases annually. CPAR Uganda's qualitative investigation into TB[1], indeed, explored prevalence of TB in Uganda. However, this discussion only covers its findings for Uganda's Greater Northern Region, the region. Un-credited quotes in this discussion, therefore, are of the region's respondents.

The region hosts 21 percent of Uganda's population, nearly 7.2 million people and it covers 42 percent (84,194.8 km$^2$) of Uganda's land area[2], including: Karamoja, Lango, Acholi and West Nile.

**Uganda's Greater Northern Region**

| Region / # districts / km$^2$ | | | Population # / density | |
|---|---|---|---|---|
| Karamoja | 07 | 27,528.0 | 965,008 | 35 |
| Lango | 08 | 12,793.7 | 2,061,694 | 161 |
| Acholi | 07 | 28,019.7 | 1,500,770 | 54 |
| West Nile | 08 | 15,593.1 | 2,660,667 | 171 |
| **Northern** | **30** | **83,934.5** | **7,188,139** | **86** |
| **Uganda** | **112** | **200,203.3** | **34,634,650** | **173** |

The region shares borders with the Democratic Republic of the Congo in the west, the Republic of South Sudan in the north, and the Republic of Kenya in the east. Each of these three countries has experienced unrest in the recent past; unrest that necessitated a significant number of their citizens to flee their homelands and to seek refuge in Uganda.

The region, therefore, hosts a significant number of refugees – living in refugee camps and others living within communities as ordinary Ugandan citizens do.

[1] *Details on the CPAR Uganda qualitative investigation into TB are contained in its two reports titled:* ***"Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda (2017)"****, and* ***"Findings of Qualitative Investigation into Pulmonary Tuberculosis in the Greater Northern Region of Uganda (2018)."*** *PDFs of both reports are available to download free from the* ***"Tuberculosis page"*** *on its website www.cparuganda.com*

[2] *Uganda population and area statistics in this discussion are from the Uganda Bureau of Statistics from the most recent population census* (The National Population and Housing Census 2014 - Main Report 2016) .

## The Region's TB Disease Burden

Using the national TB prevalence rate, it is valid to surmise that, in 2017, the region with a population of 7.2 million people had an estimated 18,000 TB cases. The belief, in fact, is strong that TB has become more widely prevalent in the region; more than it was in the past.

***"In the TB ward, the number is never reducing. The patients are increasing more and more."*** As a matter of fact, indeed, ***"a district in this region has the second highest number of MDR-TBs (patients with multi-drug resistant TB) in the country; second to Mulago and yet Mulago is a national hospital."***

Add the influx of diseased refugees, particularly from a neighbouring country in which "***the situation is just cantankerous. All sorts of diseases are there, because there is no governance there. While we are doing immunisation, to them it is: "to whom it may concern.""*** When refugees from that country come, "***they come with their all sorts of diseases."*** Some refugees were, indeed, confirmed infected with TB. ***"I suspected one refugee had TB and it was confirmed from the government hospital."***

All respondents testified knowing, within their respective communities, persons infected with TB[3]. Their knowledge of the disease varied, because among respondents were:

- TB survivors.
- Those familiar with TB through their interactions with persons confirmed or presumed infected with TB – relatives, friends, work colleagues, students, and constituents.
- Those who thought people infected with TB on the basis of folklore, such as, those who believe ***"there are people (presumptive TB cases) on the island (in one of the districts) that are unidentified and they are too many."***

The feasibility that presumptive TB cases are on the loose, living within their communities, was thought the case by 64 percent of respondents.

[3] *CPAR Uganda's briefing on research findings containing its qualitative data-set on* ***"Tuberculosis the Silent Epidemic in Uganda's Greater Northern Region"*** *is available to download free from its website.*

Of those respondents who thought so:

- 89 percent thought presumptive TB cases living within their communities included those who were untested and undiagnosed.
- 44 percent thought presumptive TB cases living within their communities included those who had been tested and were waiting for their results.
- 22 percent were sure that the TB cases living within their communities included patients who had been diagnosed and confirmed to be infected.

Some confirmed TB patients living within the communities, apparently, were not put on treatment; while others were put on treatment, but are lost to follow-up – they did not return to healthcare facilities for confirmatory testing of the effectiveness of the drug regime they were given and/or for drug refills.

Confirmed TB patients living within their communities, according to 44 percent of respondents, included those who should have been under quarantine in an isolation ward at a healthcare facility. They included those infected with MDR-TB, but who were prematurely discharged. Reportedly, a major reason why TB patients were prematurely discharged from TB isolation wards was food.

***"Sometimes, somebody is not having food. You are the one taking care of your family – both providing food for yourself and your family, it becomes hard. If we see you are strong enough, you can walk from home, we allow you go and come from home."*** Prematurely discharging confirmed TB patients on grounds of food, moreover, was done knowing that ***"once you are started on treatment, the rate at which you infect others reduces, but it is not eliminated."***

## The TB-HIV Association

The World Health Organisation (WHO) recognises that people living with HIV (PLHIV) have a high chance of being infected with TB. According to WHO (2014) ***"TB is the most common presenting illness and the leading cause of death among PLHIV."*** This, indeed, holds true in the region. Irrespective of findings of the Uganda AIDS Commission (2017) that there was a downward trend in HIV infections among Uganda's population in 2016 as compared to 2011, the Commission cautioned that ***"the burden of HIV infection in the country is still unacceptably high."*** For emphasis, for example, six percent (nearly one million people) are infected with HIV among Ugandans aged 15-49 years; this is the largest segment of Uganda's population by age.

Data in an annex to a Uganda Aids Commission report (Uganda HIV/AIDS Country Progress Report July 2016-June 2017), in fact, shows that during a 12 months period that ended July 2017, of over 134,000 persons in the region who were tested and confirmed HIV+, 17.4 percent (over 23,000) were confirmed to also be infected with TB.

**TB-HIV Infected Persons in 2017**

| Region | # TB-HIV+ |
|---|---|
| Karamoja | 19,013 |
| Lango | 1,476 |
| Acholi | 1,201 |
| West Nile | 1,696 |
| **Northern Region** | **23,286** |

The sub-region with the highest number of TB-HIV co-infected patients was Karamojo. It should be noted, however, that 93 percent of those reported by the Commission as those who were tested and confirmed TB-HIV positive in Karamoja, were from only one district, Kaabong. The number of persons the Commission reported as tested and confirmed with HIV in Kaabong were over 110,000, which if correct, means that 66 percent of Kaabong's population was infected with HIV in 2017.

Whatever the case, the number of patients that are co-infected with TB and HIV in the region is believed to be high. Indeed, 86 percent of respondents reported that they knew of or suspected persons within their communities who were TB-HIV co-infected. Perhaps this is the major reason that perpetuates a wide spread attitude[4] in the region that ***"where there is TB, there is HIV and where there is HIV, there is TB."***

Even though the two diseases are linked; and even though TB is an airborne infectious disease, which,

[4] *CPAR Uganda's briefing on research findings containing its qualitative data-set on the "**'Tuberculosis Attitude' in Uganda's Greater Northern Region"** is available to download free from its website.*

unlike HIV is curable, "***the Government is putting much interest in HIV than in TB;"*** and "***TB is almost becoming a neglected disease."*** TB is neglected in the region, to the extent that ***"the political leadership (at district local government level) are not very knowledgeable about TB."*** During local government meetings, for example, ***"people don't normally bring issues of TB out clearly,*** but instead they ***"always talk more about HIV, but not TB."***

Donor agencies are also prioritising HIV over TB and only addressing TB in the context of PLHIV. Donors support provision of TB care, primarily for the purpose of preventing TB or minimising the effects of TB among PLHIV. It is believed, for example, that the GeneXpert machines for testing for TB that were in the region were donated by the U.S. Government through its projects that are focused on PLHIV. The U.S. Mission in Kampala (2017) confirmed that its government had donated 29 machines to Uganda. The media (Namagembe 2017) quoted the U.S. Ambassador as having emphasised that the GeneXpert machines donated would be ***"especially important for people living with HIV."***

## Conclusion and Recommendations

Karamoja has much higher numbers of persons that are infected with both TB and HIV. Whereas, there is need to eradicated TB from the whole region and the Country, Karamoja, and in particular, Kaabong District, need urgent special attention, in order to identify and take action against the root causes of the exceptionally high TB and HIV infection rates in that geography.

Some refugees come into the region and into the country when they are already infected with TB. Since TB is an airborne infectious disease, and it is the Government's policy to allow refugees to live freely among Uganda's population, there is a need for mass mandatory screening of refugees.

There is a lot of cross-border movement by the citizens of East African (EA) countries, for trade and tourism, especially. This makes TB a cross-border issue. Joint EA wide efforts are needed to fight TB.

Uganda's TB management policy which allows for TB patients who should be under quarantine to be treated as out-patients needs to be reviewed, particular so, for patients that are infected with MDR-TB.

Food insecurity should not be the reason for releasing MDR-TB patients from hospital. And it is not enough to provide food rations to TB patients, because it is not sustainable. TB takes a long time to treat and cure. Food security solutions that provide food for entire households are recommended.

Having sufficient diagnostic capacity can stem the spread of TB. Undiagnosed cases and diagnosed cases that wait too long to receive treatment are worrying. There should be no undiagnosed TB cases. Diagnosing TB should be prioritised and testing turn-around times shortened.

## Works Cited

Ministry of Health. *The Uganda National Tuberculosis Prevalence Survey, 2014-2015 Survey Report.* Kampala: Republic of Uganda, 2015.

Namagembe, Lilian. "Uganda Receives Shs 500m Tuberculosis machines." *Daily Monitor*. 11 February 2017. http://www.monitor.co.ug/News/National/Uganda-receives-Shs500m-Tuberculosis-machines/688334-3808846-xmlksuz/index.html (accessed August 13, 2017).

U.S. Mission Uganda. "U.S. Government supports Uganda's TB control efforts with donation of state-of-the-art detection equipment." *U.S. Embassy in Uganda.* 17 February 2017. https://ug.usembassy.gov/u-s-government-supports-ugandas-tb-control-efforts-donation-state-art-detection-equipment/ (accessed February 19, 2019).

Uganda AIDS Commission. *Uganda HIV/AIDS Country Progress Report July 2016-June 2017.* Kampala: Republic of Uganda, 2017.

Uganda Bureau of Statistics. *The National Population and Housing Census 2014 - Main Report.* Kampala: Republic of Uganda, 2016.

World Health Organisation. *Xpert MTB/RIF for People Living with HIV.* Geneva: World Health Organisation, 2014.

## About the author

Ms. Norah Owaraga is the Managing Director (MD) of CPAR Uganda and on its behalf she authored this discussion. Owaraga is a cultural anthropologist, in which capacity she functioned as the Social Scientist for the ***"Tuberculosis: Working to Empower the Nation's Diagnostic Efforts (TWENDE)"*** Consortium, under which CPAR Uganda conducted its investigation. She 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.

## Acknowledgements

**Prof. Christopher Garimoi Orach** (PhD, MPH, MMed, DPH, MBChB, & Certificate in Health Emergencies), in his capacity as the CPAR Uganda Board Chair, voluntarily provided direct technical supervision to the author in both her roles as the CPAR Uganda MD and as the TWENDE Social Scientist. Prof. Orach is a medical doctor; a professor of public health; and is currently the Deputy Dean of the Makerere University School of Public Health.

**Mr. Alex B. Okello** (MBA, BSc, DipEdu, DipPA, FCIS), in his capacity as the CPAR Uganda Finance Committee Chair, voluntarily provided direct administrative supervision to the author in her role as the CPAR Uganda MD. Mr. Okello 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.

CPAR Uganda 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.**

***Disclaimer: Whereas, the EDCTP Association and the European Union provided funding for the TWENDE Project, the views herein expressed in this discussion, a product of the TWENDE project, are not necessarily those of the EDCTP Association or those of the European Union.***