

**Policy Brief
to
Health Committee of Parliament
of
The Republic of Uganda**

**End Tuberculosis Now!
TB is a Burden, an Enormous Health
Challenge to the People, the Public
Health System, and Uganda's Economy**



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

CPAR Uganda Ltd
Plot 5, Makerere Road, Lira Municipality
P.O. Box 820 Lira, Uganda
www.cparuganda.com

1. Statement of the Issue

Pulmonary tuberculosis (PTB) that is otherwise sometimes referred to as TB of the lungs is a disease that has been eradicated in most parts of the world, but continues to persist in Uganda. PTB, moreover, is a highly infectious, debilitating and deadly airborne disease, but which is preventable and curable. As is the case with all airborne infectious diseases, early diagnosis of PTB and the isolation and treatment of those infected with active mycobacterium TB is the most efficient way to slow down PTB infection rates and or to prevent its geographical spread.

Emerging findings from a comprehensive qualitative investigation into PTB in Uganda that was conducted by CPAR Uganda Ltd (CPAR)¹ agree with the Uganda national TB survey² estimates that thousands of people infected with PTB in Uganda have not been tested. There is, indeed, good reason to believe that thousands of Ugandans infected with active PTB are unaware what disease afflicts them, or if they are aware they are unaware of the dire consequences of not seeking diagnostic and treatment services. Persons infected with active PTB, some unaware, live freely within their families and communities unknowingly spreading the deadly disease.

The national TB survey estimates that Uganda has 87,000 TB cases annually; an annual prevalence rate of 253/100,000; and a rate that is higher than had previously been thought. It is feasible that on the basis of a false assumption previously held that Uganda had a lower TB prevalence rate, the World Health Organisation (WHO) declared Uganda no longer among countries with a high TB burden. High level Government of Uganda (GoU) officials, such as the Minister of Health, Hon. Dr. Jane Ruth Aceng (2017), moreover, acknowledge that Uganda's *"TB burden has continued to cause an enormous health challenge to the people of Uganda and is a big public health challenge to the health system in Uganda. Additionally, TB presents an economic challenge and impacts negatively on the livelihood of our people."* It is therefore baffling that Uganda national budgets for TB management³ are consistently underfunded.

According to the WHO annual TB report for the financial year 2016/2017, for example, the budget for Uganda's national TB programme is US\$ 54 million (nearly 196 billion shillings), of which only 29% is funded, leaving 71% (about 139.2 billion shillings) not funded. Worse still, of the 29% (about 56.9 billion shillings) of the national TB programme budget that is funded, only 3% (about 5.9 billion shillings) is covered from domestic sources; while 26% (about 51 billion shillings) is covered by external grant funding; confirming Ministry of Health (2010) reports that global initiatives provide Uganda with the bulk of resources needed for TB.

Emerging findings from the CPAR investigation confirm how underfunding is forcing medical personnel in Uganda to do their work in risky conditions, while they are handling infectious PTB patients; or to refuse to do their work. Unfavourable work conditions were among the basis for the recent doctors' strike. As Dr. Muniini Mulera (2017) aptly describes the status quo as Uganda's medical personnel forced to *"make do with substandard resources to provide a service to sick citizens."* Participants in the CPAR investigation shared that due to insufficient funding, for example, front line medical personnel, such as nurses, are chronically not provided with the requisite protective gear, such as suitable masks; a basic need that is required when medical personnel are handling patients with highly infectious airborne diseases.

Medical personnel in Uganda who take the risk and do their work under substandard working conditions are unnecessarily exposed to getting infected with PTB. When infected they are, at best, incapacitated by illness for long periods of time; PTB treatment takes anywhere from six months to over a year. At worst, Uganda loses its medical personnel to death, such as was the case with Dr. Lukwiya, for example.

¹ Read more on the scope of the CPAR TB Study (2017) in its report *"Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda"* that is submitted with this policy brief.

² Details in Ministry of Health (2017) report on *"The Uganda National Tuberculosis Prevalence Survey, 2014-2015."*

³ See analysis of Extracts from WHO TB Country Profiles for Uganda for 2014 to 2017 submitted with this brief

Dr. Lukwiya contracted and died of Ebola. An analysis by Khanakwa (2016) concludes that Dr. Lukwiya was infected with Ebola, an airborne disease such as TB, because he was overworked, fatigued and sleep deprived, which resulted in him forgetting to put on goggles. The emerging findings from the CPAR investigation indicate that medical personnel, indeed, feel underpaid and overworked; and according to the CPAR investigation participants, this is due to insufficient funding.

Insufficient funding for PTB healthcare services is the reason that PTB diagnostic services are not easily accessible to ordinary Ugandans as they should be. Emerging findings from the CPAR investigation indicate that suspected PTB cases often have to travel long distances and at a huge cost on their time and their family financial resources, in order to access appropriate diagnostic services. Admittedly, PTB sufferers are not alone in facing inaccessible health services, because poor health infrastructure and services provision in Uganda cuts across nearly all diseases. The Ministry of Health (2010), in fact, has long known this anomaly and it has prior observed that: ***“although 72% of households in Uganda live within five kilometres from a health facility, utilisation is limited due to poor infrastructure, inadequate medicines and other health supplies, the shortage and low motivation of human resources.”***

Ugandans travel long distances seeking TB diagnostic services because most of the lower level health facilities – health centre Is, health centre IIs and health centre IIIs – are equipped, if at all, with obsolete light microscopes used to diagnose PTB by the smear microscopy technique. The national TB Survey, moreover, found that ***“smear microscopy, the main TB diagnostic test in the country, misses about 60% of the cases”***; a finding which led the Ministry of Health (2017) to conclude that there is a ***“need to update the country’s TB screening and diagnostic algorithms.”*** There are more efficient and more effective technologies, funding permitting, which would be the better option with which to equip Uganda’s lower level health centres.

GeneXpert TB test machines are powerful and highly sensitive molecular diagnostic machines which, for example, according to findings of a study in India (Sreeraj 2015), can detect five times more cases of drug resistant TB. In Uganda, a country with a high PTB burden, emerging findings from the CPAR investigation indicate an average national ratio of physical presence of GeneXpert machines to the population of 1:353,000; and in some regions it is even much higher – the highest ratios being in the range of 1:553,000 in Lango and 1:574,000 in Bunyoro.⁴ The CPAR investigation finds that ratios of TB diagnostic machines to the population often go even higher because diagnostic machines often spend long periods of downtime – weeks, months, or even years – during which they do not function.

Under prioritising funding budgets and allocations for PTB healthcare services results in untold suffering for thousands of Ugandans⁵. Many endure long and painful periods of illness, during which they are mostly treated inhumanely. PTB is a slow silent killer and its sufferers watch their body waste away and their spirit broken, until they succumb to death. Those who get tested late, treated, heal and survive, often live the rest of their lives with permanent damage to their vital internal organs – particularly the lungs; which renders them less productive human beings to the detriment of the quality of their lives and Uganda’s economy. Those who are fortunate to get tested early and adhere to the treatment regime, heal and pretty much continue to live a normal life; and this is how it should be.

It is disheartening to realise, and to confirm, that the issue of focus in this policy brief has for decades been known and is appreciated by high level GoU officials within the Ministry of Health, in particular, and seemingly within other relevant government bodies and departments, such as the Ministry of Finance and the National Planning Authority. In the second national health policy, for example, the Ministry of Health observed that ***“inadequate financial and human resources, capital investment and management issues have resulted in the public sector being unable to fulfil its mandate of providing medicines to meet the requirements of universal access to health care.”*** PTB health care services, particularly PTB diagnostic services, are among those that the public sector has failed to sufficiently provide to the people of Uganda. It is imprudent to allow this status quo to continue.

⁴ See table of Uganda GeneXpert TB Testing Machine Coverage submitted with this brief.

⁵ Read a Uganda Citizen’s Story: The Case of a TB Survivor submitted with this brief.

2. Policy Recommendations

The Health Committee of Parliament should:

- a) Pay closer attention to and closely scrutinise the annual budgets of the Ministry of Health and ensure that:
 - Sufficient budget provisions are included in those budgets for PTB healthcare services.
 - The Ministry of Health, in particular, and the GoU, in general, emulates the Government of the Republic of Rwanda, and ensure that the budgets for the national TB programme are covered 100%, irrespective of sources of funding. This should start immediately with the remaining six months of the 2016/2017 financial year.
- b) Monitor closely the Ministry of Health's quarterly budget performance and ensure that:
 - Funds budgeted for PTB healthcare services are not diverted at both the Central Government level and at the District Local Government level; not even to other emergency health services, for PTB in itself is a disease that warrants 'emergency treatment'.
 - Timely and sufficient releases of funds (in-cash or in-kind) are made to the departments, institutions and hospitals that are implementing PTB programmes and that are providing PTB healthcare services.
- c) Review procurement policies that govern acquisition of services and materials for diagnostic machines and medical supplies with the view of reducing costs by:
 - Where it is possible, to decentralise to health facilities the budgets and decision making for acquisition of machine service contracts, supplies, and materials. Centralised procurement of service contracts and cartridges for GeneXpert machines, for example, is a major reason why the machines stay non-functional for long periods, emerging findings from the CPAR investigation reveal.
 - In the spirit of the "**Buy Uganda Build Uganda Policy**" (Ministry of Trade, Industry and Cooperatives 2014), enforcing domestic sourcing and procurement of materials that can be made in Uganda – such as smear applicator sticks – in wooden form or in a wire loop form, and sputum collection plastic cans. If such materials are currently not being produced in Uganda, incentives (tax breaks or whatever) should be provided to local Ugandan investors to produce them. This is the prudent, more viable, more frugal and more sustainably longer-term policy decision.
- d) Liaise with other policy makers – other committees of parliament, parliament as a whole, or even the executive, with the intention to advocate for management of PTB to be considered as a crosscutting issue of concern to all. Policies for building awareness on handling and management of PTB should be enacted and implemented for all public institutions – parliament, detention centres, the armed forces, schools, public transport, houses of worship, the 'modern' closed markets, hospitals, the work place and all places that groups of people gather. All public institutions should plan and budget for the management of PTB within institutions and for the users of these institutions, so as to stem its spread and infection rates.
- e) Cause a review of Uganda's 'open door' policy of unrestricted free entry and settlement of refugees, particularly those originating from countries in which their healthcare services are likely non-functional due to civil strife, for example. At the very minimum, Uganda should request assistance from the United Nations for necessary diagnostic machines, equipment, supplies and human resource for mass screening of all refugees at points of entry, in order to identify those who are infected with PTB, isolate and treat them. This will reduce the strain on local government budgets of refugee host districts.

3. Appendices

The following documents are submitted together with this policy brief:

- Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda (CPAR Uganda Ltd 2017)
- Extracts from WHO TB Country Profiles for Uganda for 2014 to 2017 (Owaraga 2017)
- Table of Uganda GeneXpert PTB Testing Machine Coverage (Owaraga 2017)
- A Uganda Citizen's Story: The Case of a Tuberculosis Survivor (Owaraga 2017)

4. Recommended Sources of More Information

Aceng, Jane Ruth. "Foreword." In *The Uganda National Tuberculosis Prevalence Survey, 2014-2015*, by Ministry of Health, 3. Kampala: Republic of Uganda, 2017.

CPAR Uganda Ltd. *Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda*. Research Report, Lira: CPAR Uganda Ltd, 2017.

Khanakwa, Pamela. "'If i die, let me be the last': Reflecting on Dr. Lukwiya and Uganda's Efforts Against Ebola." *Kujenja Amani*. 02 May 2016. <http://forums.ssrc.org/kujenga-amani/2016/05/02/if-i-die-let-me-be-the-last-reflecting-on-dr-lukwiya-and-ugandas-efforts-against-ebola/#.WiZTzFWWbIW> (accessed December 05, 2017).

Ministry of Health. *The Second National Health Policy - Promoting people's Health to Enhance Socio-Economic Development*. Policy, Kampala: Republic of Uganda, 2010.

Ministry of Health. *The Uganda National Tuberculosis Prevalence Survey, 2014-2015*. Survey Report, Kampala: Republic of Uganda, 2017.

Ministry of Trade, Industry and Cooperatives. *Buy Uganda Build Uganda Policy*. Policy Document, Kampala: Republic of Uganda, 2014.

Mulera, Munini. "Doctors' strike deserves win-win solution, not threats of arrest." *Daily Monitor*. 14 November 2017. <http://www.monitor.co.ug/OpEd/columnists/MuniiniMulera/Doctors-strike-deserves-winwin-solution-threats-arrest/878676-4185226-11x7hlxz/index.html> (accessed December 12, 2017).

Owaraga, Norah. *A Uganda Citizen's Story: The Case of a Tuberculosis Survivor*. Research, Kampala: CPAR Uganda Ltd, 2017.

Owaraga, Norah. *Extracts from World Health Organisation Tuberculosis Country Profiles for Uganda*. Research, Kampala: CPAR Uganda Ltd, 2017.

Owaraga, Norah. *Table of Uganda GeneXpert PTB Testing Machine Coverage*. Research, Kampala: CPAR Uganda Ltd, 2017.

Sreeraj, T.K. "Indian Government to tackle tuberculosis with 300 new GeneXpert diagnostic machines ." *SCOOP WHOOP*. 01 June 2015. <https://www.scoopwhoop.com/news/300-tb-diagnostic-machines-to-be-introduced/#.5i35fqi8f> (accessed August 07, 2017).

Disclaimer: This policy brief is among the products of the Tuberculosis: Working to Empower the Nations' Diagnostic Efforts (TWENDE) project that is part of the EDCTP2 programme supported by the European Union. Whereas, the EDCTP Association and the European Union provided funding for the TWENDE Project, the views herein expressed are not necessarily those of the EDCTP Association or those of the European Union.