

ADDRESSING THE DOUBLE BURDEN OF DIABETES AND TUBERCULOSIS IN UGANDA USING A PARTICIPATORY APPROACH

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How this policy brief was developed:

This policy brief was developed by John Smith based on the research project “*Designing a pill pack for integrated Tuberculosis and Diabetes Care in Uganda: the first iteration*”. The research was conducted under the guidance of the School of Global Public Health, New York University, USA, and benefited from the incentive grant for young researchers provided by the World Health Organization Global NCD Platform and UNITAR’s Defeat-NCD Partnership in collaboration with the Alliance for Health Policy and Systems Research.



What is this policy brief about?

This policy brief presents the findings of a participatory prototyping study to test an informational pillbox for integrated tuberculosis - diabetes mellitus care in Uganda. It proposes a cost-effective patient education intervention to improve patient understanding of diabetes mellitus within the established tuberculosis treatment framework.

Who is this policy brief for?

This policy brief primarily targets national, regional and local health policy-makers in Uganda, however other decision-makers, practitioners and researchers interested in the integrated care for tuberculosis – diabetes mellitus may find the content of this policy brief relevant.

This policy brief includes:

- Description of the double burden of tuberculosis and diabetes mellitus in Uganda
- Methodology and key findings of the intervention prototype study
- Opportunities for integrating the proposed patient education intervention in Uganda

This policy brief does not include:

- Strategies to implement the provided recommendations
- Comparison of several policy options and recommendations on the best option

PROBLEM STATEMENT

- The incidence of double burden of tuberculosis (TB) and diabetes mellitus (DM) continues to rise globally, with low- and middle-income countries shouldering a significant proportion of the cases.
- The presence of diabetes mellitus (DM) in tuberculosis (TB) patients triples the chance of progression from latent TB to active infection, and patients with the double burden of TB-DM experience a five-fold decrease in successful TB outcomes.
- In Uganda, one of the 30 countries with the highest burden of TB, the prevalence of DM in individuals with TB is 8.5%.
- TB-DM patients in Uganda often lack knowledge and certainty about their DM diagnosis.
- TB-DM patients in Uganda face stigma related to their TB diagnosis.
- Our study showed that both, patients and providers desire additional tools to support DM education in TB clinics.

IMPLICATIONS

- There is a critical need for an integrated infrastructure for TB-DM care in Uganda. It is essential that a participatory approach is adopted in making the required infrastructural changes.
- Patient education interventions to improve understanding of DM within the established TB treatment framework may serve as cost-effective solutions.
- The proposed informational pillbox tested in two Ugandan clinics demonstrated a high level of acceptability among patients and healthcare providers.
- The proposed information pillbox aligns with the goals of Uganda's National Plan and the Diabetes Compact by integrating NCD care into existing health structures while addressing the needs of the target population.
- The pillbox can potentially provide a cost-effective solution for integrating TB-DM care into existing TB infrastructures in Uganda.

1. FRAMING THE PROBLEM

BACKGROUND

Diabetes mellitus (DM) and tuberculosis (TB) are intersecting conditions that threaten population health in many low-and-middle-income countries [1,2].

Diabetes mellitus is a non-communicable, chronic metabolic disease associated with elevated blood glucose levels [3]. The global prevalence of DM was 10.5% in 2021 [4]. Low- and middle-income countries currently bear 80% of this burden [2], and there has been a rapid increase in DM prevalence in sub-Saharan Africa [5].

Tuberculosis is a communicable disease caused by *Mycobacterium tuberculosis* which most commonly presents as a pulmonary disease [6]. The global incidence rate of TB increased by 3.6% in 2021, as 10.6 million TB cases were recorded [7]. The incidence of tuberculosis patients with DM is currently at 15.3% [8]. With the predicted rise of DM

patients increasing by 48% to 629 million by 2045, and a 163% increase expected for Africa [8], the incidence of double burden of TB-DM is expected to rise.

In Uganda, one of the 30 countries with the highest burden of TB in the world, the prevalence of DM in individuals with TB is 8.5% [9-11]. The presence of DM in TB patients triples the likelihood of progression from latent TB to active infection, and patients with the double burden of TB-DM experience a five-fold reduction in successful TB outcomes. This underscores the need for improved capacity to treat diabetes as part of integrated management with TB treatment.

Moreover, our previous research has shown that TB-DM patients in Uganda often lack knowledge and certainty about their DM diagnosis, and face stigma associated with their TB diagnosis. With the increasing rates

of DM among Ugandan patients initiating treatment for TB, timely and adequate management of DM can improve TB treatment outcomes and quality of life for persons with TB. Yet most patients in Uganda are unfamiliar with DM.

This policy brief presents a cost-effective patient education intervention to improve patient understanding of DM within the established TB treatment framework. The prototype of the proposed intervention has been tested in two TB clinics in Uganda, and the results indicate that it can potentially provide a cost-effective solution for integrating TB-DM care into the existing infrastructures of TB in Uganda.

Where can I find out more about diabetes and tuberculosis?

The **Global Health Observatory**, a public health observatory established by the World Health Organization, monitors and shares data on global health, including statistics by country and information about specific diseases and health measures, presented in comprehensive analyses and with interactive visualizations.

The **International Diabetes Federation**, a non-profit umbrella organisation of more than 240 national diabetes associations in 161 countries and territories, collects and shares information about diabetes, promotes standards of care and prevention, and provides education for people living with diabetes and their healthcare providers.

The **International Union Against Tuberculosis and Lung Disease** is a global scientific organization committed to creating a healthier world for all, free of tuberculosis and lung disease. Bringing together clinicians, managers, policy makers, front-line workers and implementers, scientists, patients and survivors, advocates and civil society, the Union strives to end suffering due to tuberculosis and lung diseases by advancing better prevention and care.



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METHODS AND DATA SOURCES

Setting

For more than a decade, the Uganda Tuberculosis Implementation Research Consortium (U-TIRC) has been conducting research to bridge the gap between TB evidence and practice in Uganda. Led by both Ugandan and international researchers from institutions such as NYU, Yale, Johns Hopkins and UCSF, U-TIRC hosts several TB studies supported by private foundations, USAID and the National Institutes of Health (NIH). Several studies focus on examining access to NCD care among people with TB and/or HIV. One such U-TIRC study, "Predicting and Preventing Tuberculosis Treatment Failure in an Emerging Co-Epidemic of HIV, Diabetes, and Tuberculosis", led by Dr. Mari Armstrong-Hough (NYU) and Dr. Achilles Katamba (Makerere University), followed a prospective cohort of 285 patients starting pulmonary TB treatment at public sector TB units in Kampala, the urban capital of Uganda. During the U-TIRC study, individuals with indications of DM were referred to the on-site NCD clinic for DM treatment.

Intervention prototype

We developed an informational pillbox for TB-DM patients that discreetly conceals medication while providing daily access to visual information on DM management. The pillbox is intended to be used to structure a brief nurse-administered counselling session for people co-diagnosed with TB and DM, and then as a daily reminder of the importance of managing DM as the patient progresses through TB treatment. The informational pillbox prototype was designed to look like a notebook, with narrative, graphically represented information about DM to the left, and a pocket to the right to hold TB medication. The graphical narrative was illustrated by a Ugandan medical illustrator to ensure contextually relevant content. The educational material is designed to remind users about the key concepts of DM that the nurses introduce to individuals during DM counselling. The pillbox also included a calendar at the end of the educational content and some lined, blank pages for notes. The pillbox thus offered both diabetes information and afforded participants discrete storage for their medication.

Data collection and analysis

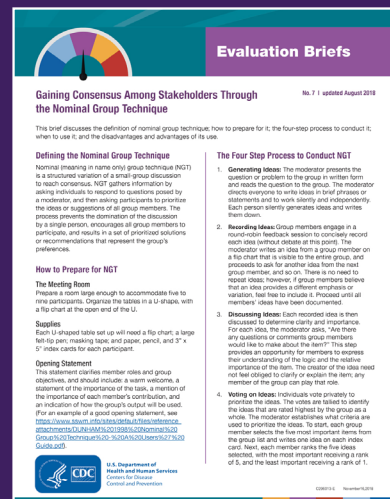
We used a novel method of participatory prototyping to optimize the informational pillbox for DM education and counselling in TB-DM clinics. The participatory prototyping approach builds on elements of human-centred design and on social science principles to create a rapid, equitable and inclusive method of intervention design. This approach to intervention development combines theory-informed intervention design with a process of iterative optimization led by end-users. It enables researchers to develop feasible, efficient, stakeholder-engaged interventions within a short period. The process involves developing a theory-informed, context-specific intervention prototype with a multi-stakeholder design team which is delivered to end users. Intercept interviews are conducted by a team of social scientists and summarized for the design team. The design team then uses

the Nominal Group Technique to generate and prioritize adaptations for the intervention. This process is repeated at least three times to generate the final context-optimized intervention.

The first iteration of the prototype was distributed among study participants who used it for up to two weeks at two TB clinics in Kampala, Uganda. Semi-structured focus group discussions and in-depth interviews were carried out to understand participant experiences with the initial prototype. An international multi-stakeholder team was debriefed with the findings of these interviews. A semi-structured focus group discussion was also carried out with a group of Ugandan physicians and TB clinic nurses to understand the feasibility of the use of the informational box during the DM counselling process in TB clinics.

Where can I find out more about the Nominal Group Technique?

An evaluation brief by Centers for Disease Control and Prevention (CDC) **“Gaining Consensus Among Stakeholders Through the Nominal Group Technique”** discusses the definition of the technique, how to prepare for it, the four-step process to conduct it, when to use it, and the disadvantages and advantages of its use.



2. KEY FINDINGS

High acceptability of the informational pillbox among participants

The informational pillbox was well received by the participants who indicated that they liked having the pillbox as a way of storing their medication. It was considered “nicer” than the usual method of dispensing medication in polythene bags. It also offered the patients a certain level of discretion about their TB diagnosis. One participant mentioned that when asked about the contents of the pillbox, he preferred to say that it was for DM, and not TB, thus avoiding any anticipated expected TB stigma.

High degree of use of the pillbox by participants

Functionally literate participants were able to follow the graphical presentation of the informational content and demonstrated knowledge retention after two weeks of using the pillbox. Most of the participants interacted with the pillbox on a regular basis and mentioned adopting health protective behaviours based on the information shared in the informational pillbox. They also mentioned sharing the information with friends and family. The calendar at the back of the pillbox was used by some participants to keep track of their appointments and their daily medication intake.

The degree of familiarity with, and use of, the informational pillbox related directly to when the participants received the pillbox during their TB treatment journey. Those who received it at an earlier point in their treatment timeline demonstrated more familiarity with and use of the pillbox. Those who received it at a later point in their journey were more detached from it and were less familiar with its contents.

Design of the pillbox

We identified three major design challenges from the focus group data: the need for political neutrality, a preference for more durable materials, and concerns about size.

Participants expressed a clear **need for political neutrality** in the design of the pillbox. The informational pillbox prototype was red and yellow, colours that the design team had borrowed from the Ugandan flag. However, these two colours are also associated with two political parties in the country. Participants requested that a neutral colour be used so that the pillbox not be mistaken for political propaganda.

Pillbox durability was the second challenge we identified. Participants mentioned that the portable nature of the pillbox allowed them to travel with it. However, they had faced challenges with the pillbox material which did not travel well. They also mentioned the need for the pillbox to be waterproof in the rain.

Another challenge that arose was the **size of the pillbox** itself – due to recent changes in the packaging of the prescribed TB medication, it was difficult to fit the entire course of medication into the pillbox pocket.

Additional information requested by users

Participants asked for additional information on TB symptoms and for content to address TB stigma. They further requested that a similar pillbox be provided to individuals undergoing preventive TB therapy.



Photo: WHO

3. IMPLICATIONS AND RECOMMENDATIONS

We found that the informational pillbox was successful in both of its main objectives – providing educational information about DM to individuals with both TB and DM, and providing a discreet storage solution for TB medication. We believe this offers an opportunity to better harmonize the management of TB and DM in Uganda.

Uganda's *National Multisectoral Strategic Plan for the Prevention and Control of Noncommunicable Diseases (2018-2023)* outlines an action plan to halt the rise of diabetes by 2025. Strategic Action Area 4 of the plan is to ensure a comprehensive and integrated management of noncommunicable diseases (NCDs). Key priority actions in this area include integrating NCD care within other health systems and raising public awareness of NCDs. As a member of the WHO Global Diabetes Compact (cite), Uganda is working to put those living with diabetes at the centre of the decision-making that impacts their lives.

Currently, there is limited infrastructure for integrated care of TB and DM in Uganda. Our research shows that patients and providers

want additional tools to support DM education in TB clinics. The information pillbox was well accepted by people with a dual diagnosis of TB and DM, as well as by clinicians, and could potentially be integrated into the TB care structure.

However, there is an opportunity to expand the content of the information pillbox to include information about TB symptoms and ways to cope with TB stigma. Our Diabetes Information Pillbox can be used as a dual-purpose tool, providing a discrete packaging option for TB medicines while also providing critical knowledge about DM and DM management. The pillbox can potentially provide a cost-effective solution for integrating TB-DM care into existing TB infrastructures in Uganda.

The Diabetes Information Pillbox aligns with the goals of the National Plan and the Diabetes Compact by integrating NCD care into existing health structures while addressing the needs of the target population. It is the actualization of strategic action area 4 of the National Multisectoral Strategic Plan (2018-2023).

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