

End TB in Uganda

Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda



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

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1. Introduction and Background

On behalf of CPAR Uganda Ltd, henceforth in this document to be referred to as CPAR, Ms. Norah Owaraga (MSc. Dev. Mgmt. (Open)), CPAR's Managing Director, authored this report in December 2017 on the qualitative investigation in Uganda for the research and advocacy project "***Tuberculosis: Working to Empower the Nations' Diagnostic Efforts (TWENDE)***." She authored this report also in her capacity as one of the Principal Investigators (PIs) for TWENDE – she was the TWENDE expert Social Scientist and its Qualitative Investigator for Uganda.

1.1. TWENDE Objectives

The text appearing in this document in bold and in italics and that is without a citation, CPAR has derived from the approved TWENDE planning documents. However, the emphasis, the underline, is by CPAR, in order for CPAR to indicate areas in which CPAR understood as areas that TWENDE planned for CPAR's expertise to make a contribution towards achieving.

TWENDE was a two-year project that took place from January 2016 to December 2017 in three East African countries: Uganda, Kenya and Tanzania, and with a mission to:

Create a platform for accelerating uptake of diagnostic and clinical research innovation through uncovering and addressing the impediments for implementation of health research innovations.

In order to achieve its mission, TWENDE had the following five overall specific objectives:

- a) ***Evaluate the extent of the implementation of two WHO (United Nations World Health Organisation) approved molecular diagnostics and pathway to implementation of one in pipeline, the rapid MYcobacterial Treatment Response Assay (MYTRA).***
- b) ***Explore the benefits of these methods to the health care system and the attitude of health care staff and administrators to the funding of the tests.***
- c) ***Unravel the impediments to wider uptake of the effective TB (tuberculosis) diagnostics and seek both local and international avenues to overcome the obstacles.***
- d) ***Engage policy makers on their stake in accelerating uptake of research innovations.***
- e) ***Capacity building through equipping and training knowledge transfer officers and regional user groups (clinicians and laboratory technologists) to sustain the translation of research output to public domain and offering expert advice on policy formulation.***

TWENDE is a study that went ***beyond the laboratory frontiers to assess the extent of implementation of molecular diagnostics for TB and to explore reasons why in places the assays are unavailable.***

TWENDE was convinced that the achievement of its objectives would enable:

- ***National policy makers to make policies that unlock the barriers and increase uptake of effective diagnostics.***
- ***Technology developers to refocus development to cost-effective platforms that meet the challenge on the ground.***
- ***International agencies to focus support not only on development and optimisation but also expanding implementation.***

1.2. Work Packages

TWENDE's intervention was divided into three overall programme work packages (WPs):

- **WP1:** *Evaluation of molecular diagnostic usage and implementation*
- **WP2:** *Engagement of policy makers and public*
- **WP3:** *Creation and empowerment of knowledge transfer units and training*

1.3. Funding Partners

TWENDE was funded by the European & Developing Countries Clinical Trials Partnership (EDCTP) Association as project number CSA-2014-283 under the EDCTP's second programme, EDCTP2, which in turn was funded by the Horizon 2020 European Union Funding for Research and Innovation.

1.4. CPAR's Role

CPAR signed an EDCTP *Accession Form for Beneficiaries* in which it agreed to become beneficiary 102332 in the Grant Agreement CSA-2014-283 between the University Court of the University of St. Andrews, which is the TWENDE Consortium Coordinator, and the EDCTP for implementation of TWENDE. By signing the accession form, CPAR agreed to *implement the grant in accordance with the Agreement*.

CPAR's role in the implementation of TWENDE, as can be deduced from the underlined text of the TWENDE objectives above, was primarily to contribute towards ensuring a high impact TWENDE qualitative investigation that would:

- *Uncover and address the impediments for implementation of health research innovations.*
- *Explore the attitude of health care staff and administrators to funding of TB medical tests.*
- *Unravel the impediments to wider uptake of effective TB diagnostics.*
- *Engage policy makers.*
- *Explore reasons why in places TB assays are unavailable.*

Therefore, CPAR's specific role was defined as follows:

Norah Owaraga, the CPAR Uganda Ltd Managing Director, is a cultural anthropologist and an expert communicator who will provide Social Sciences expertise to the consortium. Norah will take the lead of WP2.

She will:

- *Provide expertise for designing the necessary qualitative data collection tools – questionnaires, interview guides, focus group discussion guides, etc; and in ensuring the appropriate utilisation of the tools for data collection as required in WP1.*
- *Lead in advising on the composition of and creation of focus groups and workshops; and in the organisation of the sessions.*
- *Participate in authoring policy briefs.*
- *Participate in advising on how TWENDE can best package, launch and disseminate its publications for maximum effect.*

CPAR and Ms. Owaraga were vetted by TWENDE funding partners and the following relevant authorities and were found competent for the job:

- University of St. Andrews School of Medicine Ethics Committee acting on behalf of the University's Teaching and Research Ethics Committee (UTRECT).
- Uganda National Council of Science and Technology (UNCST) and de facto, therefore, The Office of the President of the Republic of Uganda.

2. Participants

2.1. Investigators

Ms. Owaraga conducted the TWENDE qualitative investigation for Uganda.

Professor Doctor Christopher G. Orach (PhD, MPH, MMed, DPH, MBChB, & Certificate in Health Emergencies) is the CPAR Board Chair. As the Board Chair, on behalf of the CPAR Board of Directors, he is the supervisor of the Managing Director and therefore he was one of Ms. Owaraga's volunteer administrative supervisors as she conducted the TWENDE investigation. Professor Orach is a well read and a highly qualified medical doctor; and he is a professor of public health with accolades of academic achievements and qualifications, including being the current (2017) Deputy Dean of the Makerere University School of Public Health. In his capacity as an academic, in addition, he was Ms. Owaraga's volunteer mentor as she conducted the TWENDE investigation.

Mr. Alex B. Okello (MBA, BSc, DipEdu, DipPA, FCIS) is the CPAR Finance Committee Chair. On behalf of the CPAR Board of Directors, therefore, he was Ms. Owaraga's second volunteer administrative supervisor as she conducted the TWENDE investigation. Mr. Okello is a highly qualified and an experienced civil servant who currently (2017) is 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. At the start of TWENDE, in 2016, he was the Permanent Secretary of the Ministry of Works and Transport.

The CPAR TWENDE team (Ms. Owaraga, Professor Orach and Mr. Okello) conducted the TWENDE qualitative investigation in Uganda in close consultation and in collaboration with the following TWENDE overall PIs, who are all affiliated to the University of St. Andrews: **Professor Stephen Henry Gillespie**, Professor of Medicine; **Dr. Ewan Chirnside**, Director of Knowledge Transfer Centre; and **Dr. Wilber Sabiiti**, Senior Research Fellow in Medicine.

2.2. Field Research Regions

CPAR divided Uganda into four TWENDE geographic research regions as follows:

- **North** – hosting a population of over 7.2 million Ugandans that are residing in 30 districts that are located in Karamoja, Lango, Acholi and West Nile sub-regions of Uganda.
- **East** – hosting a population of nearly 9.1 million Ugandans that are residing in 32 districts that are located in Teso, Sebei, Bugisu, Bugwere, Samia, Bunyole, Jopadhola and Busoga sub-regions of Uganda.
- **South** – hosting a population of over 9.5 million Ugandans that are residing in 24 districts that are located in Buganda, Buuruuli and Kooki sub-regions of Uganda.
- **West** – hosting a population of over 8.9 million Ugandans that are residing in 26 districts that are located in Bunyoro, Rwenzori, Ankole and Kigezi sub-regions of Uganda.

The statistics that CPAR utilised in determining TWENDE geographic research regions are of the findings of the most recent Uganda population census of 2014 as it was conducted by the Uganda Bureau of Statistics (2016); and the 112 districts of Uganda that existed as of January 2016.

2.3. Data Collection Tools

The TWENDE study design used both quantitative and qualitative approaches. Its investigation tools, thus, included those for primarily generating quantitative data and those for primarily generating qualitative data. CPAR, as it was planned, provided its expertise and significantly contributed in shaping the design of TWENDE data collection tools; which tools received ethics approvals from UTRECT and also from multiple relevant institutions and governmental authorities in Uganda, Tanzania and Kenya. The TWENDE data collection tools included: a survey questionnaire, interview guides, focus group discussions and policy workshops guidelines.

2.4. Respondents

TWENDE conducted an online survey during the second half of 2016 and the first half of 2017. During the period April to July 2017, CPAR collected ‘new’ TWENDE qualitative data through conducting interviews and focus group discussions. TWENDE policy workshops in a 5 in 1 event were conducted by CPAR on Monday, 27th November 2017. A total of 291 respondents participated in these TWENDE data collection activities, thus generating ‘new’ TWENDE data for Uganda as follows:

2.4.1. Survey

TWENDE survey data, as was received by CPAR from the University of St Andrews, reveals that responses for Uganda were received from 81 technocrats who responded on behalf of 81 of the 112 Uganda district local governments; a 72 percent response rate. The responding districts host 70 percent (over 24.3 million) of Uganda’s population and are fairly proportionately spread throughout Uganda’s geographic divisions.

Uganda TWENDE Survey Respondents

Regions	The Population (Districts and people hosted)		The Survey Respondents (Districts and people hosted)	
North	30	7,230,961	20	4,054,906
East	32	9,094,960	28	7,698,945
South	24	9,569,119	16	6,932,590
West	26	8,939,355	17	5,671,601
Uganda	112	34,834,395	81	24,358,042
		Percentages:	72	70

2.4.2. Interviews

CPAR interviewed a total of 85 individuals that it randomly and yet purposively selected from the four TWENDE research regions for Uganda and who were representative of all TWENDE research interest groups. Of the interview respondents, 71 percent (60 out of 85) were technocrats - in the civil service and a few private practitioners; 19 percent were politicians serving in public office; and ordinary community members, including TB patients and TB patient care givers, made up the remaining 10 percent.

Of the interview respondents, 60 percent (51 out of 85) were asked and answered a question about their age. The majority, 43 percent of them, were aged 39 years and below; 25 percent were aged 40 to 49 years old; and 32 percent were aged 50 years and above.

See more detailed information on the interview respondents in the table that follows.

Uganda TWENDE Interview Respondents

Region	Gender			Roles				Age			
	M	F	ToT	T	P	C	ToT	50+	40+	39-	ToT
North	11	3	14	9	5	0	14	2	2	4	8
East	19	8	27	18	5	4	27	6	7	5	18
South	9	7	16	11	2	3	16	6	3	3	12
West	16	12	28	22	4	2	28	2	1	10	13
Totals	55	30	85	60	16	9	85	16	13	22	51
Percentages:	65	35	100	71	19	11	100	32	25	43	100

M = male, F = female, ToT = total, T = technocrats, P = politicians, and C = community members

2.4.3. Focus Groups

CPAR conducted four focus group discussions in three TWENDE Uganda research regions. A total of 87 individuals constituted the groups, of whom the majority, 56 percent (49 out of 87) were women.

Uganda TWENDE Focus Groups

Region	Gender			Roles			
	M	F	ToT	T	P	C	ToT
North	13	8	21	0	1	20	21
East	14	13	27	0	0	27	27
South	11	28	39	16	0	23	39
West	0	0	0	0	0	0	0
Totals	38	49	87	16	1	70	87
Percentages:	44	56	100	18	1	80	100

M = male, F = female, ToT = total, T = technocrats, P = politicians, and C = community members

2.4.4. Policy Workshops

Of the 70 representatives of various institutions and bodies – governmental and non-governmental - that CPAR invited to participate in its TWENDE policy workshops, 54 percent accepted and honoured the invitation.

Participants in Uganda TWENDE Policy Workshops

Invited Constituencies	ToT	Attended		P	A	H	ToT	M	F	ToT
		ToT	%							
North	44	28	64	10	10	8	28	21	7	28
East	4	1	25	0	1	0	1	1	0	1
South	19	8	42	0	7	1	8	7	1	8
West	3	1	33	0	0	1	1	0	1	1
Total	70	38	54	10	18	10	38	29	9	38
			%	26	48	26	100	76	24	100

ToT = total, P = politicians, A = Administrators, H = Health Experts, M = male, F = female,

The participants in the CPAR held TWENDE policy workshops included 32 leaders – health experts, administrators, and politicians – representing 13 district local governments, national government institutions, universities, private hospitals and civil society organisations; and the Investigator with a documentation and logistical support team of six; thus making a total of 38 participants. The administrators were the majority, 48 percent (18 of 38), followed by equal percentages – 26 percent (10 of 38) each – of politicians and of health experts. The majority of the participants, 76 percent (29 of 38), were men.

2.4.5. Reach

The majority of the direct respondents were in leadership positions in the civil and public service of Uganda. Ultimately, therefore, it is valid to extrapolate and to conclude that their responses are inevitably representative of the views of the varied constituencies that they serve and that they represent. This conclusion is supported by the following facts:

- The majority of the respondents were highly experienced civil servants and politicians who each had medium term (five to 10 years) or long term (11 years and more) work experience.
- Most of the respondents, in addition, had worked or had served in multiple leadership positions and in multiple geographies of Uganda.

It is reasonable, therefore, to assume that the views of the direct respondents are a true reflection of the different shades of Uganda, in terms of its geographical dimensions, politics, diverse ethnicities, gender dynamics, age demographics, different social economic groups, and all TWENDE interest groups, in general.

2.4.6. Legitimacy

The respondents were dominated by technical personnel and politicians and hence the voice of the duty bearers was significantly represented. CPAR deliberately ensured that TWENDE Uganda focus groups were dominated by ordinary community members and thus ensured that the voice of the rights holders was also significantly represented.

Similarly, CPAR deliberately practiced positive gender discrimination in favour of women in constituting TWENDE focus groups for Uganda. This it did in order to reduce the gender imbalance among TWENDE respondents; and de facto assured a more gender representative sample to the best of its ability. The population of Uganda is 51 percent female, according to the most recent Uganda population census. Nevertheless, expectedly, the majority of the respondents were men, since gender disparity and inequality prevail in Uganda's work force. A Uganda country gender assessment in 2015 by the United Nations Development Programme, for example, found Uganda's female to male ratio to be 44:100 for chief executives and senior officials; and 56:100 for professionals, in general.

It is also not surprising that the majority of the respondents were young adults, considering the findings from the most recent Uganda population census that Ugandans aged 30 years and below make up 78 percent of the population.

In accordance with ethics standards for empirical research studies, TWENDE was required to prove that the respondents to its study did so voluntarily and with informed consent. Prior to conducting each interview, CPAR administered consent forms and shared information sheets; and its investigators presented letters of introduction to authorities, respondents and other stakeholders. CPAR obtained verbal consent from respondents who participated in focus groups and policy workshops and required each participant to register. CPAR, therefore, obtained authentic focus group and workshop participation lists.

Authenticated consent forms and participation lists are archived within CPAR, under lock and key. CPAR may only share them with TWENDE funding partners and the University of St. Andrews, if so requested, and strictly only for the purpose of financial and academic audits. Otherwise, CPAR is ethically obliged to protect the personal information and the individual identities of the respondents.

3. Findings

CPAR has begun the process of turning TWENDE qualitative data for Uganda into findings. The TWENDE qualitative data set for Uganda is too small for automated computer analysis to be the efficient choice. The analysis is therefore being done manually, using ‘hand tabulation’ - whereby the data is typed into the computer and is being manually ‘manipulated’ for the purpose of categorising and coding it.

3.1. Establishing Data Sets

It is expected that completed data sets – statistical spreadsheets and coded text documents - on TB in Uganda resulting from the TWENDE project, in particular from CPAR’s TWENDE activities, will be ready in six months or so (June 2018). At the very latest by mid December 2018 CPAR will be in the position to publish the data sets in a manner that allows wider access to others. In the meantime, CPAR remains open and willing, at its discretion, to honour or not requests from others for partial qualitative data for use in authoring publications – policy briefs, opinion pieces, academic papers and other forms of writing that fit within the objectives of TWENDE.

The process that CPAR is using in order to establish TWENDE data sets on TB in Uganda is as follows:

3.1.1. Transcribing

The recordings of all the interviews, the focus group discussions and the policy workshop discussions will be transcribed into text. For the most part, transcribing is pretty much a direct copy of the recording, since the bulk of the interviews; two of the focus group discussions; and all of the policy workshop discussions were done in English. For the most part, CPAR has opted to transcribe the recordings in their entirety and not only selected sections. Only four interviews were conducted in Ugandan languages (three in Ateso and one in Luganda) and two of the focus group discussions were conducted in Ugandan languages (Luganda and Lusoga). Translation to English and transcription are being done at the same time; meaning that the available transcript will be only the English language version.

3.1.2. Coding and Interpretation

An inductive approach is being utilised in order to gain insights and understanding from the data and so there are no pre-defined rigid coding categories that CPAR is using. The coding categories are emerging from the text as it is analysed. Descriptive coding of each transcript is being done immediately after each transcript is completed. In order to build a theory and in order to draw conclusions, more focused and interpretative coding will be done when all transcripts have been descriptively coded.

3.1.3. Categorical Data

TWENDE planned that *qualitative data from the above assessments and discussions (qualitative investigation) will be converted into categorical data for quantification purposes*. The conversion of qualitative data for Uganda is in progress as the transcribing and descriptive coding progresses. An analytical framework, table in an excel spreadsheet, is being established and the converted data from each transcript is being entered into the table right after it is transcribed and descriptively coded.

3.1.4. Descriptive Statistics

The TWENDE plan is that *descriptive statistics will be used to analyse the data at country and inter-country level*. Generating descriptive statistics from the Uganda TWENDE qualitative data is on-going.

3.2. Publication and Dissemination

It is CPAR's TWENDE mandate to engage policy makers with the view to raise consciousness among them of the impediments for implementation of health research innovations, in general, and the impediments to wider uptake of TB diagnostics in Uganda, in particular. During the next one year (December 2017 to December 2018), therefore, CPAR will actively engage in policy advocacy through authoring and disseminating publications and through participation in public debate.

The publications that CPAR expects to author, at the very minimum, include:

- Opinion pieces and news articles
- Policy briefs
- Policy backgrounders
- Research Reports
- Peer reviewed academic papers for publication in academic journals

CPAR intends to target its policy advocacy towards the Health Committee of Parliament and through the Health Committee to other relevant committees of parliament and to the Ministry of Health. This means that CPAR will ensure that all its publications resulting from the TWENDE project will be formally presented by to the Health Committee. CPAR, furthermore, will seek audience with the Health Committee, in order, to make a formal presentation on TB in Uganda to members of parliament.

The primary dissemination channels which CPAR will utilise in its policy advocacy on TB in Uganda, in addition to the Health Committee, include:

- Printed hard copies of publications formally circulated to the relevant authorities of all Uganda district local governments.
- Online PDF versions of its publications CPAR will make available for downloading through its website and other appropriate relevant online sites that may agree to publish them as well.

Social media platforms and traditional media platforms will be utilised by CPAR in order to generate discussions among the general public around issues on TB in Uganda as raised in the CPAR TWENDE publications.

To document and to share more details on its policy engagement activities CPAR will publish a separate TWENDE policy engagement report.

4. Conclusion

Overall, CPAR is satisfied that it has successfully implemented its TWENDE role and activities in Uganda, in spite of unforeseen challenges, but which challenges it successfully navigated. The major events that had the potential to negatively impact CPAR's TWENDE activities in Uganda are the polarising efforts in 2017 to amend the Constitution of the Republic of Uganda that have generated a lot of tensions in-country. CPAR carefully and skilfully navigated through unforeseen challenges and is confident that its TWENDE qualitative investigation is of high quality and its findings are a sound basis for better policy making and implementation.

Disclaimer: This report is among the products of the 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.