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# Childhood TB: The Elephant in the Room

## SEMINAR REPORT

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# **Childhood TB:** The Elephant in the Room

SEMINAR REPORT

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# Acronyms

ACSM	Advocacy, Communication, and Social Mobilization
DR-TB	Drug-resistant Tuberculosis
DST	Drug-susceptibility Testing
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
IGRA	Interferon-Gamma Release Assays
IMCI	Integrated Management of Childhood Illness
INH	Isoniazid
IPT	Isoniazid Preventative Therapy
LAM	Urine Lipoarabinomannan Test
LPA	Line Probe Assay
MDR-TB	Multidrug-resistant Tuberculosis
MTB	Mycobacterium Tuberculosis
NDOH	National Department of Health
NTP	National Tuberculosis Control Programme
PCR	Polymerase Chain Reaction
PHC	Primary Health Care
RIF	Rifampicin
TAM-TB	T-cells activation marker – TB assay
TB	Tuberculosis
URC	University Research Co., LLC
USAID	United States Agency for International Development
WHO	World Health Organization

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# Executive Summary

The landscape of tuberculosis (TB) diagnostics continues to change as the science of molecular diagnostics advances. Currently available molecular assays have greatly improved turnaround times for diagnosis and antimicrobial susceptibility testing of *Mycobacterium tuberculosis*. However, the impact of these assays on the programmatic management of TB still needs to be comprehensively evaluated, and challenges surrounding the diagnosis of TB in children remain. TB disease in children under 15 years of age is a public health problem of great significance in many parts of the world. In South Africa, approximately 15 – 20% of all TB cases occur amongst children and it is among the top five underlying cause of death in children under 15 (USAID Fact Sheet 2014). Unlike TB in adults, infants and young children are more likely to develop life-threatening forms of TB disease such as TB meningitis and disseminated TB. Identifying and confirming the diagnosis of paediatric TB and MDR-TB remains particularly challenging due to the difficulty of collecting sputum specimens and other factors, such as the paucibacillary nature of the disease in children. Therefore, finding innovative ways of identifying and diagnosing TB in children is crucial in the fight against the disease.

On 18 September 2014, the National Department of Health (NDOH), the University of Pretoria, and the USAID TB Program South Africa convened a special seminar bringing together diverse stakeholders to discuss and initiate further debate to improve optimization of the current diagnostic tools. The goal of the seminar was to share experiences and build consensus around the need for multi-sectoral action on the latest issues and developments in TB diagnosis, particularly for paediatric TB. The key objectives of the seminar were to:

1. Strengthen diagnostics services for effective management of TB in children;
2. Promote multi-sectoral partnerships to increase the scale and implementation of TB diagnostics services; and
3. Exchange knowledge and current best practices while providing heightened advocacy for TB in children through the “We Beat TB” Campaign.

The seminar was divided into the following three main sessions:

## **Session 1: Rapid Diagnosis of TB in Children Wouldn't Be Possible: Fact or Theory?**

Session 1 gave an overview of the gaps, challenges and progress in the diagnosis of paediatric TB. The presentation focused on evaluating new technologies and approaches of the GeneXpert diagnostic tool in children. The session also assessed the South Africa TB diagnostic algorithm, asking it works in the context of South Africa and the challenges and lessons learned in using the new technology. It identified areas of expansion and improvement in TB diagnostics in general as well for children in particular. It concluded that new technologies are important but do not replace the need for age-disaggregated data to assess the burden of TB in children in order to find innovative and evidence-based solutions to address paediatric TB. New technology also does not replace the need to render the adult source non-infectious.

## **Session 2: Reflections from the NDOH Laboratory Summit held on 18 – 19 November 2013: An Overview of Lab Summit Recommendations**

Session 2 was a panel discussion convened by experts who attended and contributed to the discussion at the National Summit on TB Diagnosis held on 18 – 19 November 2013 in Pretoria. The discussion identified areas of collaboration between the public and private sectors, and also identified the gaps in the public sector that need further engagement and solutions in the fight against TB in children.

## **Session 3: Advocacy for TB in Children: Building the Momentum on Getting to Zero TB in Children**

Session 3 focused on raising awareness of the issue of TB in children, not only at a community level but among health care workers (HCW). The presentations asked whether TB in children was receiving sufficient attention and whether current TB policies translate into practice. The session concluded that there is a need to go back to basics – to train and mentor HCW as well as the community about TB and children. The advocacy campaign by the USAID TB Program South Africa “We Beat TB” was presented as a best practice on how to advocate for better service for children, raise awareness about TB and children, and influence policy changes. Advocacy messaging and awareness, however, depend on stakeholder engagement with the media.

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Therefore, support is required from clinicians that work on TB and children on a daily basis.

The following key outcomes were generated from the workshop:

1. Activities for expansion of TB diagnostics for children were identified;
2. Public private collaboration in TB diagnostics was identified;
3. Consensus was reached on promoting innovative approaches to increase advocacy for TB in children using the current “We Beat TB” Campaign strategies in collaboration with all stakeholders.

This seminar report provides a summary of the session presentations, issues discussed, and key outcomes.

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# Session One: Rapid Diagnosis of TB in Children Wouldn't Be Possible: Fact or Theory?

Session Chair: Dr. Robert Makombe, USAID TB Program South Africa

## Presentation 1: Addressing the Gaps on Childhood TB: The Role of the NDOH

**Ms. Patricia Ntsele, NDOH**

Research has shown that the human immunodeficiency virus (HIV) and TB contribute significantly to the burden of disease faced by South Africans, especially resource-poor and vulnerable groups. The main risk factors include poor nutritional status, immune suppression in children infected with HIV, and long duration of exposure to TB. While stabilization in the management of HIV has occurred, the burden of TB is continually rising, prompting more effort by the NDOH to address HIV and TB in an integrated manner.

The latest data from the NDOH showed that there were 349,582 cases of TB in 2012 (NDOH, 2013). Although it is known that most deaths in children under five are due to TB and other respiratory diseases, the actual burden of TB in children is unknown because of under-diagnosis and under-reporting of TB in children. This hinders appropriate prevention and treatment efforts and prevents widespread adoption of proper infection control processes.

There are several ways in which TB can be prevented in children:

1. There is a serious need to intensify TB case finding for children less than 15 years of age;
2. Infection control practices should be integrated into TB, HIV and MCH adolescents services;
3. TB case finding should incorporate isoniazid preventative therapy (IPT);
4. Treatment outcomes for children less than 15 years of age should be recorded for better quality control and safety of treatment.

There are many cases of TB in children that are missed in South Africa. TB diagnosis needs to be scaled up drastically for children under 15 years of age and age-disaggregated data analysis should be conducted to assess the burden to enable the development and implementation of evidence-based interventions.

## Presentation 2: Challenges and Progress in the Diagnosis of Paediatric TB

**Professor Simon Schaaf, Stellenbosch University**

There are various challenges related to diagnosis of paediatric TB. First, TB in children is underestimated. As a result, children presenting with a cough are not considered as TB cases until it is too late. Second, it is difficult to confirm TB in children due to low volumes of specimens for culture and low number of organisms (paucibacillary disease) present in paediatric TB cases. The majority of paediatric TB cases are diagnosed without microbiological confirmation. In our context, microbiological confirmation is important as it helps to confirm TB in difficult cases – for example, uncertain lung pathology, HIV-infected children, and extra pulmonary TB. The microbiological confirmation also helps to confirm drug resistance if a source case has DR-TB and to determine drug-susceptibility testing (DST) in children with unknown source cases, especially if they have poor responses to first-line treatment. The third challenge is under-recording and under-reporting. In Cape Town, only 60% of confirmed childhood TB cases diagnosed in a tertiary hospital were found in the electronic register. No deaths were recorded and only a third of TB meningitis cases were registered. We are therefore missing the most serious cases that could assist in understanding the disease burden in areas of high prevalence. (Du Preez K, Public Health Action 2012).

There is a need to go back to basics by encouraging HCW, including doctors, to diagnose TB, record and report. Diagnosis also means a need to establish whether the case is an old or a new infection. Without new technologies, a comprehensive (conventional) approach to diagnosis in children would require the following:

1. History of chronic symptoms (coughing)
2. History of TB contact (establishing a long history of family members being sick of TB and/or died of TB)
3. Clinical examination (growth assessment)

4. Tuberculin skin testing and Interferon-Gamma Release Assays (IGRAs)
5. Chest Radiography
6. Bacteriological confirmation
7. Histology
8. HIV testing (high prevalence areas of patients at risk)
9. Scoring systems and diagnosis algorithms.

Notwithstanding the various challenges outlined above, there has been progress made in TB diagnostics. A summary of recent developments in TB diagnostics is provided below.

Firstly, the introduction of the GeneXpert, which replaces smear microscopy, but not culture, is great progress. The WHO 2013 Policy Update on 13 paediatrics studies on 2603 children showed sensitivity of Xpert vs. culture for M. tuberculosis detection from respiratory samples (66% - Specificity 98%) as well as sensitivity of Xpert vs. culture for detection of Rifampicin resistance: (86% - Specificity: 98%). For pulmonary TB in children, it is recommended that Xpert MTB/RIF be used.

Secondly, it has been discovered that PTB culture – positive cases can be identified by stool Xpert. One stool Xpert is equivalent to 1 IS or 1GA Xpert which resulted in 33% sensitivity vs. all culture plus cases (Walters et al, PIDJ 2012; Nicol et al CID 2013).

Thirdly, there has been progress in diagnosis by using automated liquid culture and DST in children. However, it is acknowledged that culture and DST takes longer but it provides the best results (30 – 70%) on 10 – 100 CFU/mL culture. Phenotypic and genotypic DST can be done on culture isolates, with genotypic DST providing more rapid results. If automated liquid culture and DST is available, it should be done with or without Xpert MTB/RIF because children usually have smear negative disease and Only 60% smear negative, culture positive cases will be identified by Xpert.

Finally, progress has been made in the development of line probe assays (LPA), which are DNA strip-based tests that use PCR and reverse hybridization methods for rapid detection of mutation associated with drug resistance. The detection threshold of the test is 130 -150 CFU/mL. The test confirms M. TB complex and provides DST for both INH and RIF. The problem with this rapid diagnosis is that it needs laboratory set up and more skilled staff to avoid the risk of cross contamination. The advantage of LPA is the ability to identify the mutation conferring resistance to INH which could assist in choosing the correct

drugs. T-cells activation marker – TB assay (TAM – TB) is a rapid and accurate blood test that has the potential to improve the diagnosis of active TB in children (Lancet ID September 1, 2014).

It is noted that Urine Lipoarabinomannan (LAM) tests should not be used in TB diagnosis as it has insufficient sensitivity and specificity to diagnose HIV positive and HIV negative children with TB (Nicol MP et al 2014 & Blok N et al 2014).

## Presentation 3: Is the GeneXpert MTB/RiF Child-Friendly?

**Dr. Nazir Ismail, Centre for Tuberculosis, NICD**

Noting the challenge in diagnosing children with TB, we should be careful of over-diagnosis, as this may lead to inappropriate treatment. The GeneXpert is very useful in diagnosing TB in children. The WHO Policy Update 2013 is clear in that Xpert MTB/Rif is to be used to diagnose pulmonary TB and rifampicin resistance in adults and children. The test can be used as an initial diagnostic test for suspected MDR and HIV-associated TB rather than smear, culture or DST. It can also be used to test everyone who is suspected of having TB, although it is acknowledged that there are resource implications related to GeneXpert diagnosis.

Overall, GeneXpert is better than smear and faster than culture as IS/NGA sensitivity is 66% better than culture. It also provides drug resistance information. The preliminary comments are that the test yields poor result in public health clinics that have poor clinical standards. GeneXpert requires more training of HCW at the clinical level Therefore, although GeneXpert is a good innovation in TB diagnosis and is useful in diagnosing children with TB, it must be emphasized that using the test does not exclude dealing with the adult source.

## Presentation 4: The South Africa TB Diagnostic Algorithm: An Overview of the Evidence

**Professor Bernard Fourie, University of Pretoria**

The South Africa TB diagnostic algorithm, as outlined in the National Tuberculosis Management Guideline 2014 and following WHO policy recommendations, stipulates that:

1. Xpert MTB/RIF should be used in preference to conventional microscopy and culture as the initial diagnostic test in testing cerebrospinal fluid specimens from patients suspected of having TB meningitis.

2. Xpert MTB/RIF may be used as a replacement test for usual practice (including conventional microscopy, culture, and/or histopathology) for testing of specific non-respiratory specimens (lymph nodes and other tissues) from patients suspected of having extra pulmonary TB.

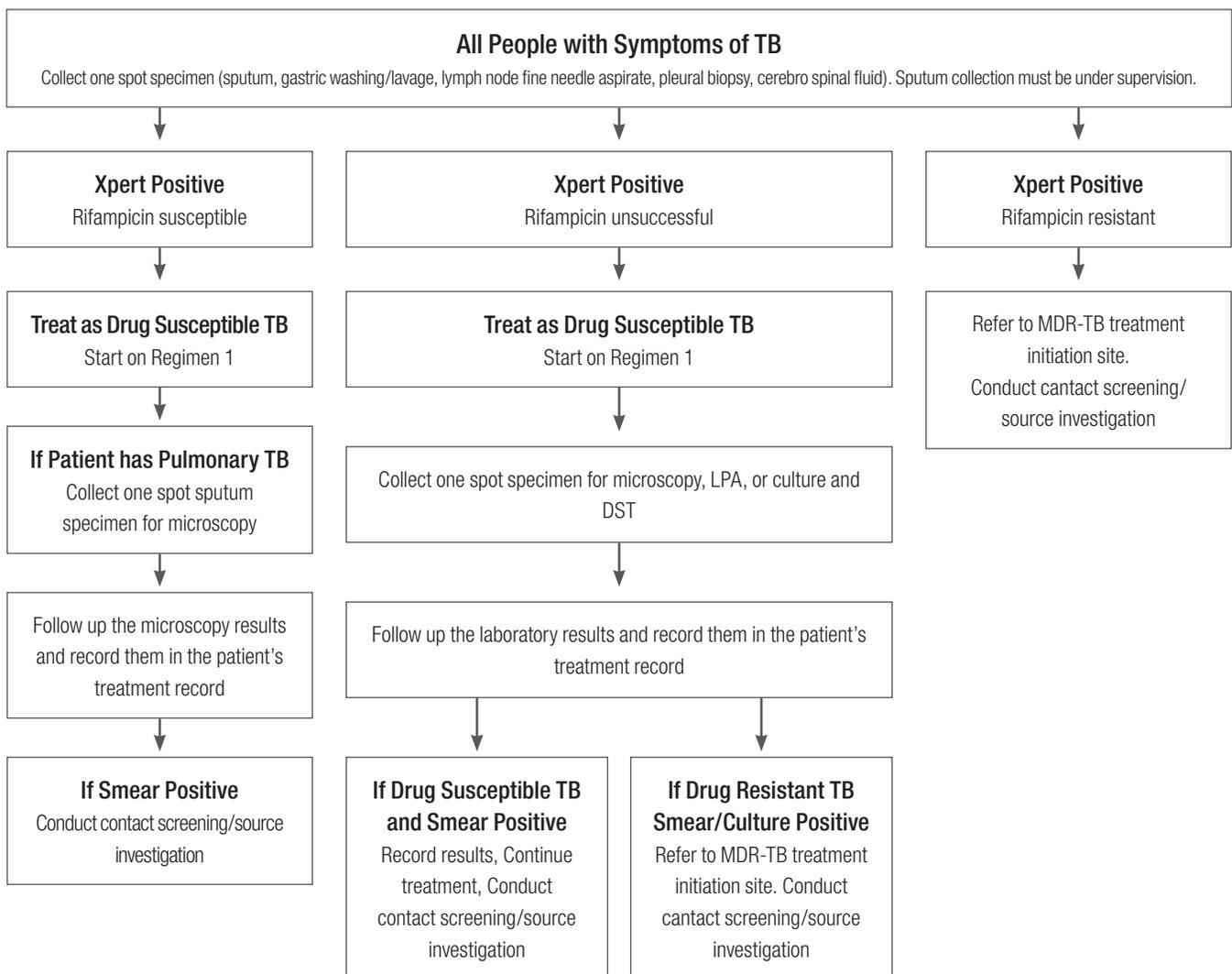
Figure 1 is the revised algorithm for TB diagnosis, drug susceptibility testing and management of the patients based on the test results. All individuals who present with symptoms of pulmonary TB should have at least one sputum specimen examined for bacteriological confirmation of TB disease. Rapid tests for confirmation of drug resistant TB such as Xpert or LPA are recommended for early triaging and treatment initiation for patients with DR-TB. Culture and DST will still be

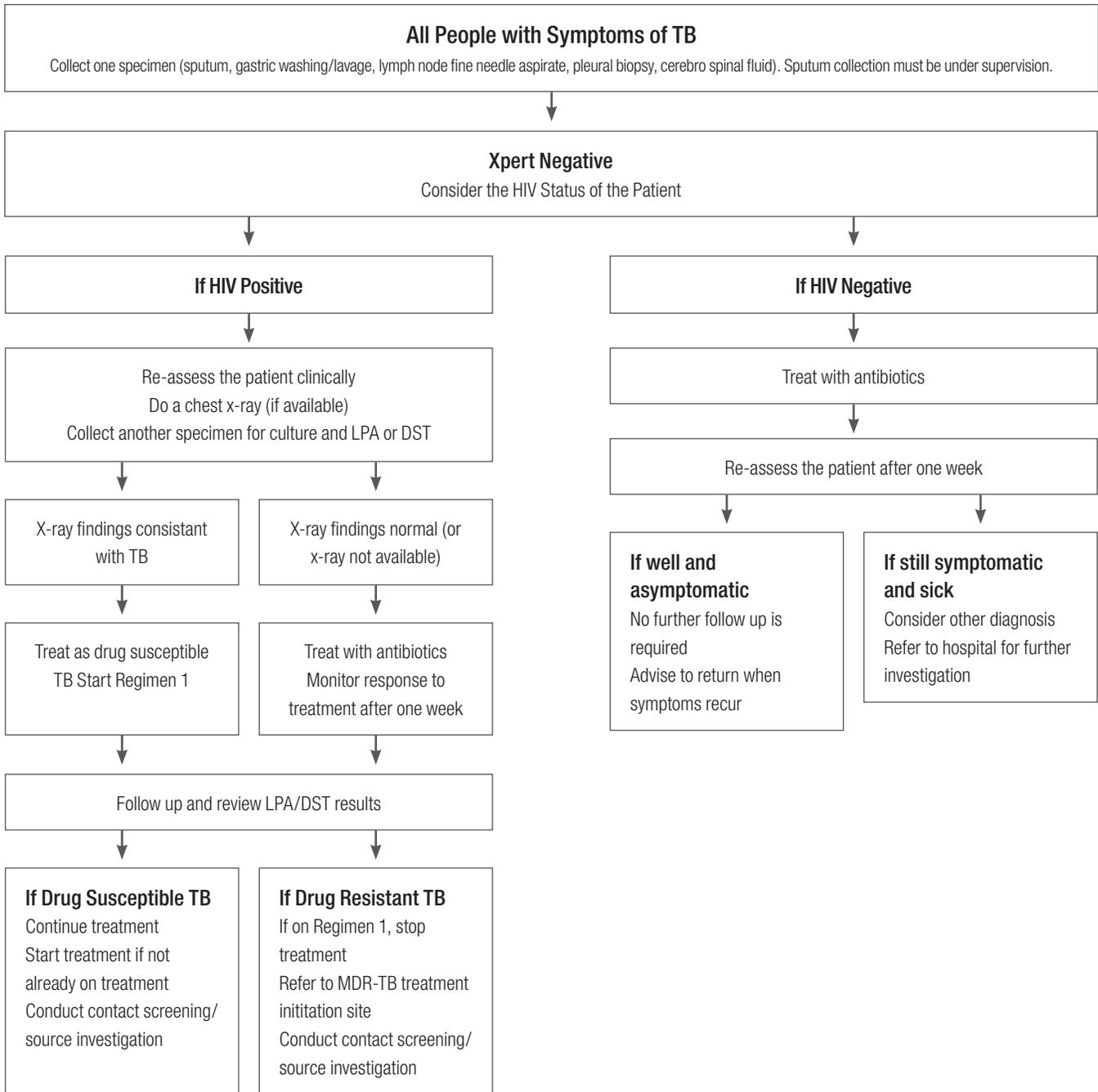
used to confirm MDR-TB and resistance to second line drugs, smear microscopy will be used for monitoring progress on treatment [National TB Management 2014].

The National TB Management Guideline 2014 also provides for the use of LPA Diagnostic Algorithm on high risk patients where rapid diagnosis of MDR-TB or isoniazid resistance is required. One spot sputum specimen should be collected for smear microscopy, if AFB positive then another specimen must be collected for LPA. If smear microscopy is AFB negative, another smear for culture and LPA must be collected.

The guidelines encourage Xpert MTB/RiF in TB diagnosis rather than conventional microscopy.

Figure 1. South Africa TB Diagnostic Algorithm





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## Presentation 5: Anti-mycobacterial Susceptibility Testing: A Dip in the Gold Value

### Dr. Beki Temba Magazi, University of Pretoria

Evidence shows that there has been vast scientific improvement on HIV treatment since its discovery in the 1980s, but less has been done to improve treatment of TB. To date, we still use poor, outdated diagnostic techniques, poor, outdated treatment protocols, and very long drug regimens that place serious strain on patients and the resource-limited health system. As much as we commend the new technologies for TB diagnosis, there is a need to do more scientific research to improve TB treatment.

The suggested framework for action is as follows:

1. Identify all mutations in M tuberculosis that result in resistance to old and new drugs;
2. Collect sequenced sensitive and resistant strains to be used in evaluating new DST essays;
3. Conduct mathematical modeling to develop strategies for deployment of DST;
4. Conduct surveillance of MOx and PZA resistance;
5. Monitor clinical resistance generated during roll-out of new drugs and identify the molecular basis of the resistance;
6. Develop DST assays for the new drugs; and
7. Develop capacity to use next-generation sequencing for TB dug surveillance.

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# Session Two: Reflections from the National Diagnostic Summit, 18-19 November 2013

Panel Chair: Mr. David Mokgokolo, USAID TB Program South Africa

**Panel:** Professor Koleka Mlisana, National Health Laboratory Service  
Professor Mark Nicol, National Health Laboratory Service  
Dr. Xoliswa Poswa, Ampath Laboratories  
Dr. Keshree Pillay, Lancet Laboratories  
Dr. Thato Mosidi, TB Proof  
Dr. Ute Feucht, University of Pretoria

## Background to Panel Discussion

The NDOH and the USAID TB Program convened a National Diagnostic Summit as a platform to facilitate the sharing of research finding to inform policy. The summit was held on 18–19 November 2013. The summit was based on the following five thematic issues:

1. Key issues in introduction of new tests, operations research, evaluation of new technologies, and quality assurance;
2. Regulatory issues around application of the regulatory framework, standardization across laboratories, and pricing regulations;
3. Access and affordability, including pricing, geographical location, sharing of resources, and medical aid insurance;
4. Priorities in research to inform policy on TB; and
5. Public private partnership in TB diagnosis: priorities for client and the patient.

The summit recommended the following:

1. Development of a generic national implementation framework for review and roll out of new diagnostic tests;
2. Establishment of a multi-stakeholder national task team of experts to provide on-going guidance on the introduction of new tests or diagnostic procedures; and
3. Convening of annual meetings to follow up on implementation.

At this panel presentation, members of the multi-stakeholder national task team of experts reflected on the various thematic issues discussed at the summit.

## Panel Discussion and Comments

### *1. How can we leverage resources for improved TB diagnosis?*

As a country, we have limited resources, which mean fewer resources to liberate within this sector. The resource scarce condition prompts us to create synergies amongst ourselves to leverage on those limited resources and draw on each other's expertise. We also need to understand what is available for the work that we do and how we can best use those resources to benefit the nation, especially those most vulnerable to TB infection. TB is proving to be a serious public health problem; overall commitment can never be overemphasized.

### *2. What are the efficiencies that we can learn from the private sector that can be duplicated in the public sector?*

The main efficiencies in the private sector is the technological advances and turnaround time for tests results. However, it is noted that TB diagnosis is not very prevalent in the private sector. The tendency is that when a diagnosis is made in the private sector, patients are referred to the public sector, which increases the burden on the public sector. Private-public collaboration can reduce this burden. As it stands, regardless of the availability of molecular tests like the GeneXpert in the both the private and the public sector, the turnaround time for test results is still not at a rate that it should be. In the private sector it takes a week to get the first test result and another week to get the tests for DR-TB. This follows a week or so of treatment, depending on the availability of medical aid funds, and then a patient is referred to the public sector. The public sector takes even longer.

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### ***3. What is the private sector contribution in the fight against TB in South Africa?***

There is substantial disconnect between the private and public sector. It is well known fact that the private sector does not have a burden of TB patients. The private sector needs to coordinate more with the public sector in terms of accounting for people with TB. At the moment, patients referred to the public sector are tested again which wastes resources that are already scarce. When the private sector refers patients, they need to make medical records available to prevent further delay in initiating treatment.

### ***4. TB diagnostics, treatment, and care in the public sector – what are the challenges and what can we do?***

Diagnostics are not perfect; they are not linking sufficiently with treatment and care. Patients wait too long to get test results, especially for DR-TB. When they eventually do, there is substantial delay in initiating treatment. HCW are not educated and mentored enough to diagnose TB in children until they are very sick. The contact tracing system has collapsed, similar to what was seen in the scaling up of HIV programmes. Nurses are expected to diagnose TB when they are overburdened in providing HIV treatment, care and support. There is also insufficient, if any, social support for TB patients.

There are insufficient network systems in public health care. To follow the algorithm entails having good management tools for managers and HCW in hospitals. It also assists with patient migration and TB data. Without proper records health care facilities cannot act on potential TB cases in a timely manner.

There is no age disaggregation of data. For example, in the Tshwane district, physicians know that they have diagnosed and treated children with TB but do not know the number. There is no data available. PCR testing for babies born to HIV-positive mothers has improved over the years, but we are behind with PCR testing for TB. PCR testing for TB can assist with developing much-needed data.

### ***5. Is there a disconnect between the private and public sector?***

The following is evidence of a serious disconnect between the private and public sector:

- Records show 25% patients diagnosed with TB, but only 15% were treated. Something happens between when they are diagnosed, either in the public or private sector, and when they are supposed to receive treatment. Public and private sector systems are not communicating with each other. This is vital for patients tracing, the most important factor in the fight against TB.

- Diagnosis is easy in the private sector. Patients are also treated for a period of time then referred to the public sector to receive medication. The disconnect occurs when patients have to register to receive medication from the public sector. They are required to start the process again, as the public sector does not rely on the records from the private sector for continuing treatment. As a result, patients get frustrated and discontinue treatment.
- There is no contact list between the two sectors to trace referrals for continuing treatment and care. This is the reason why patients are tested again, which is poor planning and waste of resources.
- There is no clear indication on which facility can accommodate patients who still need hospital care. Therefore, the lack of isolation risks the spread of TB infection.
- Completed laboratory results are signed for and then sent to the nurse or physician who requested them. The public and private sectors face different challenges here. While HCW in the private sector are quick to get the printed results, there seems to be a problem in locating laboratory results in the public sector. When results are eventually located, the patient cannot be traced. As a result, they continue to spread the disease.
- TB is a communicable disease and, unlike HIV, is an airborne disease which makes it crucial for systems to communicate with each other both ways, through testing to treatment to patient tracing to care.

### ***6. Are we on the right track with TB diagnosis?***

TB diagnostics is certainly better than before, especially with regards to microbiology testing. Generally, we are seeing the same standards of tests. To improve quality, all new diagnostic innovations introduced are analyzed by a committee and recommendations are made to companies on how best to use the new technology in the health sector. It is important to note, however, that TB diagnostics has been neglected for a long time and with TB cases rising, this is an error that should never be repeated.

GeneXpert for TB testing is a good technology, but has its own challenges related to sensitivity in testing and therefore needs to be complimented by the best screening tests. Appropriate screening will establish the right treatment for patients.

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## 7. What are the outcomes we want from this meeting?

Great progress has been made since the last meeting, but the following are some of issues that we need to improve on:

- Finding a solution to the private-public disconnect. Although diagnosis is important, it does not beat treatment. Patients can be diagnosed but if they are not treated, TB disease continues to spread and children in contact with adults infected with TB suffer.
- There is still a lingering issue that the private sector overburdens the public sector. Therefore, there is a need to improve the referral system from private to the public sector to ensure efficient transfer of results for more efficient initiation or continued treatment of patients.
- Doctors and nurses are not using protective gear and equipment. We need to emphasize the importance for all HCW to wear protective equipment to avoid infection as they are needed to treat the sick.
- About 80% of people suspected of TB are placed on treatment before their culture comes back. Improving HCW training on proper screening would decrease this number and save resources for treatment.
- Systems that track people with suspected active TB should be improved so that they can start treatment immediately.
- GeneXpert is still expensive and therefore not widely accessible. As a result, it is important to go back to the basics by training and deploying HCW in communities to screen children. This includes training and mentoring HCW to screen children for TB at the facility level.
- Currently, there is more education and awareness related to HIV than TB. This gap needs to be addressed at the top so it can filter down to health facilities and then communities.
- More research needs to be conducted on patients' behavioural patterns with regard to treatment adherence because the best treatment outcome is dependent on patient behavior and knowledge. An understanding of this behavior is crucial in dealing with challenges related to patients discontinuing treatment and adherence.
- Create more awareness on paediatric TB. Delays in diagnosing children occur because HCW workers as well as communities at large still do not believe that children can be infected with TB.
- Acknowledge that messaging and awareness around issues related to TB is difficult. Therefore, there is a need to conduct on-going integrated training on childhood illnesses for HCW, including traditional healers and early childhood development caregivers in communities.
- Improve the HCW rotation system and continue mentoring HCW on how to screen, diagnose, treat and care for adults and children with TB.
- Strengthening the overall health system is crucial in the fight against all communicable diseases. A large percentage of public health resources need to focus on health systems strengthening. With regard to TB, access to information is vital; it also entails strengthening electronic database communication. An integrated data communication between laboratories, health facilities and non-governmental organizations working in the community should be created.
- The National Health Laboratory Service is able to send TB statistics reports to various public health stakeholders that are on their mailing list on a weekly and monthly basis. It is suggested that all districts and sub-district managers should be included on these reports so that they have information on who has been diagnosed.
- Age-disaggregated data is crucial in understanding the burden of TB disease in children and finding innovative and evidence-based solutions on how the public health system can deal with paediatric TB in the South African context.

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# Session Three: Advocacy for TB in Children: Building the Momentum on Getting to Zero TB in Children

Session Chair: Dr. Beki Temba Magazi, University of Pretoria

## Presentation 1: Are Children Receiving the Attention They Deserve? A District Health System Perspective

**Dr. Ute Feucht, University of Pretoria**

Chronic diseases are killing children in South Africa at an alarming rate. The various presentations have all alluded to the fact that TB epidemic in children is different in all respects, including diagnosis and treatment. Therefore, programming and implementation of projects at a facility level needs to be different. TB and HIV in children both come from adult exposure. This means that HCW need to understand paediatric TB and treat it differently. At the moment, programming and implementation focus on adults and therefore children lose out. There is a need for clarity on TB diagnostics at the implementation level. HCW need to understand the difference between preventing TB and diagnosing and treating TB. There is often confusion surrounding this distinction. Critical factors for success on TB in children are:

1. Prevention: Contact tracing and providing TB prophylaxis;
2. Proper screening and sampling: Methods like induced sputum collection need urgent attention if new technologies like the GeneXpert are to be used optimally;
3. No child with TB should miss out on HIV testing and no child with HIV should miss out on TB screening;
4. Defining the levels of care and rethinking the role of IMCI is important;
5. Understanding the linkages between hospitals and primary care will assist in finding solutions; and
6. Age disaggregated data is crucial.

## Presentation 2: Does Policy Translate into Practice? Operational Childhood TB Research

**Dr. Karen Du Preez, Desmond Tutu TB Foundation**

Supporting health systems is important for continuity of care. It is difficult to do any planning without data to help understand the burden of the disease in children. It is therefore important to focus on TB prevention in children, provider knowledge, and continuity of care, as all these three factors form proper and adequate management of TB.

The policy regarding the TB prevention is that IPT should be given to all TB exposed children under five years of age and who are HIV positive. However, research shows that in a hospital setting, 50-60% of children under 5 years of age are exposed to TB, which leads us to miss the opportunity of preventing TB in a large percentage of children. At community level, there is a very low uptake of and adherence to treatment. The best solution may be to have an IPT register.

With regard to continuity of care, policy states that continuity care pathways should be ensured which includes the availability of accurate routine TB surveillance data. However, research show that only 62% of children with TB were included in routine provincial reporting systems. A possible intervention would be to strengthen in-hospital TB referral services.

Training of HCW form a crucial part of health systems strengthening. The Kid Care Project conducted by the Desmond Tutu TB Foundation in Khayelitsha was aimed at improving essential components needed to support the cycle of routine paediatric TB care as part of health systems strengthening. The project found that knowledge about TB is not too bad, but needs to be improved in rural communities. The project concluded that: 1) proper functioning health systems are needed to ensure successful completion of the cycle of TB Care; and 2) there needs to be more operational research at a facility and community level to identify gaps,

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propose and implement interventions, and rigorously research and evaluate impact to enable us to give evidence-based advice to policy makers.

## Presentation 3: Issues Related to Diagnosis and Management of Childhood TB

### Ms. Tumi Mbengo, USAID TB Program South Africa

The challenges of contact tracing, proper diagnosis, and proper management and treatment of TB cannot be overemphasized. Although we have new technologies, lack of tools, loss of patients to follow up, and lack of access to x-rays in community clinics leading to referrals to hospitals remain problems. We need to build staff confidence in diagnosing TB at community clinic level. We also need to educate HCW on paediatric formulations and educate the community about the importance of adhering to treatment by adults. Recommendations to these challenges are:

1. Comprehensive integration trainings;
2. Revitalization of PHC Re-engineering – WBOTS;
3. Involvement of community-based organizations;
4. Clear and simplified guidelines; and
5. Availability of tools and resources to facilitate diagnosis at primary health care level.

## Presentation 4: Raising Community Awareness on TB in Children: “We Beat TB” in Children

### Ms. Lerato Legoabe, USAID TB Program South Africa

There is low community awareness that children can have TB. This requires us to raise more awareness on TB to educate the community. ‘We Beat TB’ is a national communication campaign of the USAID TB Program, implemented by University Research Co., LLC (URC). It aims to improve health-seeking behaviour among South African communities by increasing knowledge on TB prevention, encouraging early presentation for diagnosis, and treatment adherence. The campaign integrates the use of mass media and community level interventions using a communication for participatory development approach, developed by the Johns Hopkins University Center for Communication Programmes.

The USAID TB Program South Africa, as part of its work supporting the NDOH, helps to increase demand for TB services through its strategic communication program, as well as through support for community-based NGOs through its small grants program. TB in children is a priority of the National TB Programme (NTP), and the USAID TB Program is working to ensure integration of child TB into routine NTP activities. Key activities have included an assessment of the burden of TB in children; the design of a strategy to increase demand for services for TB in children; training health promoters and community health care workers on child contact tracing; and provision of IPT for children under five. The USAID TB Program develops, packages, and communicates health messages to communities through various campaigns and communication channels including radio, TV and road shows.

Designing communications to support diagnostics is difficult but not impossible. The program has utilized various methods to communicate messages related to TB and children. It launched “We Beat TB” in 2009, provided technical support to NDOH, and used animated public service announcements to get messages about TB across to a variety of audiences. The Program has worked with schools, partnered with local NGOs, and raised awareness on TB prevention and treatment by using billboards, branding on trucks, and advertisements at taxi ranks.

The USAID TB Program key advocacy efforts on TB in children have included:

1. Development of an ACSM Toolkit with a focused section on TB in children to increase partner involvement in the campaign;
2. Advocate for a dedicated section in the national TB screening book on TB in children to support contact tracing;
3. Work with local councils to host community dialogues and build community action teams to work with facilities;
4. Encourage leaders to use public platforms to speak about issues relating to the prevention of TB in children;
5. Integrate with maternal health programme and strengthen prevention efforts;
6. Engage men in the advocacy to prevent TB in children; and
7. Partner with schools and early childhood development programmes.

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USAID TB Program South Africa also incorporates capacity building into its advocacy work. The Program conducted a workshop with NGOs and selected community radio stations on issues relating to TB in children. It uses the ACSM Toolkit and campaign PSA to facilitate discussions. Through these efforts, the USAID TB Program has built the capacity of health promoters, youth ambassadors, and community care givers to: 1) host community dialogues; 2) plan and implement community events; 3) conduct door-to-door campaigns; 4) advocate to local leaders; 5) work with the media; and 6) encourage referral to services.

The success of the USAID TB Program advocacy work can be attributed continuous open and effective communication with various stakeholders and clinicians who work with TB on a daily basis. This allows the project to design and deploy TB messaging that will have the greatest impact in the targeted communities.

## Annex: Summit Agenda

Time	Activity/Session	Facilitator/Presenter
Chair: Dr Robert Makombe, URC – USAID TB Program <i>Rapid diagnosis of TB in children wouldn't be possible, a fact or theory?</i>		
08:00 – 08:30	Arrival & Registration	All
08:30 – 08:40	Welcome remarks	Prof Nontombi Mbelle, University of Pretoria
	Addressing the gaps on Childhood TB: The Role of NDOH	Dr Lindiwe Mvusi, National Department Of Health (NDOH)
	Challenges and progress in the Diagnosis of Paediatric Tuberculosis	Prof Simon Schaaf, Stellenbosch University
	Is the Xpert MTB/Rif child friendly?	Dr Nazir Ismail, Centre for Tuberculosis, NICD
	The South Africa TB diagnostic algorithm: An Overview of Evidence	Prof Bernard Fourie, University of Pretoria
	Anti-Mycobacterial susceptibility Testing: A dip in the gold value	Dr Beki Temba Magazi, University of Pretoria
	Lessons Learnt in the implementation of GeneXpert in resource poor settings	Dr Refiloe Matji, URC - USAID TB Program
	Discussions	All
10:45 – 11:15	Health Break	
11:15 – 13:00	Chair: Mr. David Mokgokolo, URC – USAID TB Program <i>Reflections from the NDOH Laboratory Summit held on 18th to 19th Nov 2013</i> Panel: Prof Mark Nicol, National Health Laboratory Service; Prof Koleka Mlisana, National Health Laboratory Service; Dr Xoliswa Poswa, Ampath Laboratories; Dr Keshree Pillay, Lancet Laboratories Dr Thato Mosidi, TB Proof Dr Ute Feucht, University of Pretoria	
	<b>Overview – Lab Summit Recommendations</b> Key issues in Quality: Introduction of new tests, operations research/evaluations and quality assurance. 1. Regulatory issues: Application of the regulatory framework / standardization across laboratories/ Pricing regulations 2. Access and affordability: Pricing/geographical location/sharing of resources/ medical aid insurance 3. Key priorities in research: identifying key research questions/ using research to inform policy 4. PPP in TB diagnostics: Priorities for the client and the patient	David Mokgokolo, URC – USAID TB Program
13:00 – 14:00	Lunch Break	
14:00 – 16:30	Chair: Dr Beki Temba Magazi, University of Pretoria <i>Advocacy for TB in Children: Building the Momentum on Getting to Zero TB in Children</i>	
	Are children receiving the attention they deserve? A District Health System perspective	Dr Ute Feucht, University of Pretoria
	Does policy translate into practise? Operational childhood tuberculosis research	Dr Karen Du Preez, Desmond Tutu TB Foundation
	Issues Related to Diagnosis and Management of Childhood TB	Ms. Tumi Mbengo, USAID TB Program
	Raising community awareness on TB in children: “We Beat TB” in children	Ms. Lerato Legoabe, USAID TB Program
17:00 – 20:00	Cocktail / networking session sponsored by BD	Becton, Dickinson & Co (BD)



