

NAIROBI STRATEGY ON TB AND HUMAN RIGHTS: MEASURING PROGRESS AND PLANNING FOR THE FUTURE MOMBASA COUNTY, KENYA

WORKSHOP
REPORT

9 - 10 AUGUST

2018

Your Website Here

Nairobi Strategy on TB and Human Rights: Measuring Progress and
Planning for the Future Mombasa County, Kenya

REPORT

9 - 10 August 2018

© KELIN



Image: Participants pose for a group photo at the workshop to measure progress of the Nairobi Strategy on TB and Human Rights. Photo taken 9 August 2018, Mombasa (Kenya).

TABLE OF CONTENTS

ABBREVIATIONS AND ACRONYMS	6
EXECUTIVE SUMMARY	7
DAY ONE: 9 AUGUST 2018	8
WELCOME AND INTRODUCTIONS: Allan Maleche, Executive Director, KELIN (Kenya)	8
OPENING REMARKS:.....	11
Viorel Soltan, Team Leader, Country and Community Support for Impact (Switzerland).....	11
KEYNOTE ADDRESS:.....	12
Justice Mumbi Ngugi, High Court of Kenya (Kenya)	12
DISTINGUISHED REMARKS FROM THE COMMUNITY:	14
Dean Lewis, Global Coalition of TB Activists, Touched by TB, International Network of People who Use Drugs & TB People (India).....	14
SESSION ONE: Progress implementing the Nairobi TB Strategy (2016 – 2018) Summary	15
Remarks by session chair, Lynette Mabote (ARASA).....	15
Brian Citro: Overview of the <i>Nairobi TB Strategy</i>	16
Progress report: The Nairobi Strategy: A human rights-based approach to tuberculosis - Vivek Divan.....	16
Plenary session	18
SESSION TWO: Documents for input and feedback.....	19
Summary	19
TB in Prisons: An introduction to the law - John Stephens.....	19
Judicial Handbook on TB, Human Rights and the Law - Brian Citro.....	20
The Declaration on the Rights and Responsibilities of People with TB (revised Patients’ Charter for Tuberculosis Care) - Timur Abdullaev	21
Plenary session	22
SESSION THREE: Group work: Feedback on draft documents and presentation of group recommendations	24
Summary	24
GROUP 1: Judicial Handbook on TB, Human Rights and the Law	24
GROUP 2: Declaration on the Rights and Responsibilities of People with TB	25
GROUP 3: TB in Prisons: An introduction to the law.....	26
SESSION FOUR: Testing and treatment justice: Access to new drugs and diagnostics for all	27
Summary	27
Matching advances with access in TB science - Dr Jennifer Furin.....	28

Video: ‘Two Countries, Two Choices’ – AIDS Free World.....	30
Plenary session	30
CLOSING REFLECTIONS.....	31
Blessina Kumar, CEO, Global Coalition of TB Activists (India)	31
DAY TWO: 10 August 2018.....	32
INTRODUCTION AND FRAMING THE CONVERSATION: Brian Citro	32
KEYNOTE ADDRESS: Justice Edwin Cameron, Constitutional Court of South Africa (South Africa).....	33
DISTINGUISHED REMARKS FROM THE COMMUNITY: Timpiyian Leseni, Founder Talaku, (Kenya)	34
SESSION FIVE: Talk Show: What’s happening in TB and human rights? A discussion with people on the frontline	35
Summary	35
Gisa Dang, Consultant, Treatment Action Group (USA).....	36
James Malar, Community, Rights and Gender Advisor, Stop TB Partnership (Geneva).....	37
Eunice Mailu: National TB Programme (Kenya).....	37
Priyam Lizmary Cherian, Legal Officer, Lawyers Collective (India)	38
SESSION SIX: Roundtable: What next for the draft Political Declaration for the UN High-Level Meeting on TB?.....	39
Summary	39
Dean Lewis, Global Coalition of TB Activists, Touched by TB, International Network of People who Uses Drugs & TB People (India)	39
Austin Obifuna, Executive Director, Afro Global Alliance (Ghana).....	39
John Stephens, The O’Neil Institute (USA)	40
Plenary session	40
SESSION SEVEN: Group work: Prioritization of activities under the Nairobi TB.....	40
PLANNING THE NEXT STEPS: Strategy session to advance a human rights based-approach to TB	40
CLOSING REMARKS, WRAP UP AND VOTE OF THANKS	42
Abdulai Sessai (Sierra Leone).....	42
Dr Jennifer Furin	42
ANNEXTURES.....	43
AGENDA	43
CONCEPT NOTE.....	46
LIST OF PARTICIPANTS.....	50

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
CSO	Civil Society Organization
HIV	Human Immunodeficiency Virus
HLM	High Level Meeting
KELIN	Kenya Legal and Ethical Issues Network on HIV/AIDS
LAM	Lipoarabinomannan
LEA	Legal Environment Assessment
MDR	Multi-drug-resistant
NEPHAK	National Empowerment Network of People living with HIV/AIDS in Kenya
OHCHR	Office of the United Nations High Commissioner for Human Rights
PLHIV	Person living with HIV
R&D	Research and Development
TAG	Treatment Action Group
TB	Tuberculosis
UN	United Nations
UNDP	United Nations Development Programme
UNOPS	United Nations Office for Project Services
USAID	United States Agency for International Development
WHO	World Health Organization

EXECUTIVE SUMMARY

On 9 – 10 August 2018, the Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN), Stop TB Partnership and Northwestern Pritzker School of Law (USA) hosted a delegation of over 30 stakeholders representing judicial officers, communities, healthcare workers, civil society organizations and scholars to take stock of progress and plan for the next phase of implementation of the Nairobi Strategy on TB and Human Rights.

The high-level stakeholder workshop dubbed *The Nairobi Strategy on TB and Human Rights: Measuring Progress and Planning for the Future* was convened with the following objectives:

- (i) To measure progress made in implementing the Nairobi Strategy on TB and Human Rights;
- (ii) To develop and finalize a work plan, and mobilize human and financial resources, to guide the next two years of implementation of the Nairobi Strategy on TB and Human Rights;
- (iii) To review the draft Patients' Charter for Tuberculosis Care and launch the new Judicial Handbook on TB, Human Rights and the Law; and
- (iv) To draft a communiqué on the importance of the Nairobi Strategy on TB and Human Rights for submission to the UN HLM on TB to be shared to the Co-Chairs.

In order to achieve its objectives, the workshop was divided into seven sessions as summarized below:

At the inception, participants were inspired by a key note address from Justice Mumbi Ngugi (High Court of Kenya) who urged participants to take the workshop as an opportunity to *'to sharpen our swords and to strategize on how we will support one another as we work collectively and individually to respond to this [TB and human rights] crisis.'*

In the first session, participants discussed the *Nairobi TB Strategy* and the progress made in its implementation. In this Session, Brian Citro and Vivek Divan shared the journey in development of the *strategy* and provided feedback on the progress made in its implementation.

In the second and third sessions, participants interrogated three crucial documents that are part of the *Nairobi TB Strategy*, that is, the *Declaration on the Rights and Responsibilities of People with TB (revised Patients' Charter for Tuberculosis Care)*: the *Judicial Handbook on TB, Human Rights and the Law*; and the *TB in Prisons: An introduction to the law*. Participants provided input and discussed the next steps in the development and roll-out of these documents.

In the fourth session, measures to achieve testing and treatment justice for people affected by TB were discussed. The session discussant Dr Jennifer Furin, *Lecturer on Global Health and Social Medicine, Harvard Medical School and DR-TB Training Network, USAID (USA)* discussed issues pertaining to new diagnostics, progress in research, new medication, access to drugs and related issues. Participants also watched a video showing the practical challenges faced by people affected by TB in the community.

On the second day, participants had an opportunity to listen to words of encouragement from Justice Edwin Cameron (Constitutional Court of South Africa) who urged participants to pause and recognize the ferocity of TB and the deaths it caused. Further, Timpiyan Leseni (Talaku Community Organization – Kenya) made distinguished remarks on behalf of communities affected by TB. Timpiyan recounted her journey as a TB patient and called on stakeholders to provide more support to communities affected by TB.

The fifth session of the workshop was a talk show discussion on what was happening in TB and human rights. The session discussants shared their various initiatives and contribution to the TB and human rights agenda. These included: the right to science; implementation of legal, gender and data assessment tools; development of TB isolation policy; litigation for access to TB medicine; and engaging parliamentarians on TB.

The sixth session was a roundtable that discussed what next for the draft Political Declaration for the UN High-Level Meeting on TB. The session discussants provided opinion on what should be done to ensure the political declaration that comes out of the UN HLM is impactful to the TB response.

In the seventh session, participants developed work plans to further implement the Nairobi TB Strategy for the coming three years. At the end of the workshop, participants adopted a communiqué that will be delivered to the UN high level meeting on Tuberculosis on Tuesday 14th August 2018. The communiqué spells out four key demands as follows: First, calls for access to TB drugs and diagnostics through World Trade Organization's TRIPS flexibilities for all who need them; Second, calls for the establishment of an effective and independent accountability mechanism; Third, the full incorporation of human rights language and content in the UN HLM Political Declaration; and Fourth, demand for civil society representation amongst plenary speakers at the UN HLM to represent those affected who must drive the TB response.

This is a report that provides a summary of the deliberations that took place during the two-day workshop.

DAY ONE: 9 AUGUST 2018

WELCOME AND INTRODUCTIONS: Allan Maleche, Executive Director, KELIN (Kenya)

Allan Maleche, the Executive Director of KELIN, and a co-convenor of the meeting started off by welcoming participants to the workshop. He appreciated participants who had travelled to attend the workshop – including from Asia, Europe, USA, and other African countries. He noted that the workshop provided an important opportunity to take forward conversations on TB and human rights.

Allan then shared his personal journey working on TB and human rights. He noted that he started his career as a lawyer in private practice before being introduced to HIV and human rights. Allan noted that his first interaction on issues of TB came as a result of a case reported to KELIN by the National Empowerment Network of People living with HIV/AIDS in Kenya (NEPHAK). NEPHAK reported that three people had been incarcerated at Kapsabet (Nandi County) for defaulting on TB medication. The report led to the eventual decision to litigate the cases to protect the rights of the TB patients. Thus Allan noted that he started his work on TB and human rights through a response to legal issues and representation of clients in court.

Let's get to know each other!

1. Name
2. Organization
3. Country
4. One exciting thing you are doing on TB and human rights?
5. If not, what would you like to work on within the strategy if you had the resources needed?



Images: Allan Maleche (right) making welcoming remarks at the workshop. (Left) A guide for self-introduction of participants.

Participants then made self-introductions by sharing exciting things that they were doing on TB and human rights. Participants also shared what they wanted to work on within the *Nairobi Strategy* if they had resources. The following is a summary of the responses from participants:

Some participants stated that they were working on:

- the declaration on rights of TB patients;
- implementation of TB isolation policies;
- legal environment assessments of TB;
- creating know your rights resources and training public health workers on TB and human rights;
- Providing treatment to MDR TB patients and training health care workers;
- Writing books to tell stories of what it was like to be isolated with TB;
- Working with Africa Judges Forum to integrate HIV and TB in judicial curriculum of judicial institutes;
- Developing stigma toolkits;
- Working to get access to better less toxic TB medication; and
- Advocating for new and better TB vaccines.

They noted that if they had resources they would work on:

- Creating awareness and mobilization of communities to know their rights;
- Changing frontline attitudes within healthcare systems;
- Incorporation of human rights approach;
- Making human rights a reality on people on the ground;
- Integrating health and human rights with a focus on holistic approach to medicines, health care workers;
- Building capacities of communities to understand human rights;
- Becoming activist lawyers to address TB using the law; and
- Support strategic litigation in communities.



Images: participants share proceedings of the workshop on social media

OPENING REMARKS:

Viorel Soltan, Team Leader, Country and Community Support for Impact (Switzerland)



Image: Viorel Soltan (Stop TB Partnership) giving opening remarks, 9 August 2018

Viorel Soltan, the Team Leader, Country and Community Support for Impact at Stop TB Partnership (Switzerland) gave opening remarks on behalf of the Stop TB, the co-conveners of the workshop.

In his remarks, Viorel noted that there was much work and advocacy that had been done in the HIV field as compared to TB. He reminded participants that from the 2001 UN High Level Meeting on HIV, tremendous progress had been made in the field of HIV – including heightened advocacy, litigation, treatment, research, among others. But that nothing of the sort had happened in the field of TB.

Viorel noted that HIV communities were empowered with knowledge of rights, and had access to rapid tests and medication but not the same with TB communities.

He emphasized the need to ensure TB communities were empowered to demand access to proper medication, and embrace the level of advocacy undertaken by the HIV communities.

Viorel noted that Stop TB was working with the *Global Fund to Fight AIDS, Tuberculosis and Malaria* (Global Fund) for progress on issues of TB.

He noted that Stop TB Partnership was uniquely positioned to work with governments, development partners, academia, CSOs, communities, among other stakeholders. And that Stop TB Partnership, which is hosted by UNOPs, works to bridge the gap between partners and bring change to TB.

He underscored the need to critically focus on the following three issues:

- (i) The need to address barriers to access to TB services;
- (ii) The need to create demand for TB services, for example, demand for proper and good quality medication;
- (iii) The need for quality services to be offered and respect for human rights, patient centered approaches.

Viorel concluded his remarks by noting that Stop TB works to empower affected communities and civil society and had several mechanisms in place for support, for example, the challenge facility for civil society, among others.

KEYNOTE ADDRESS:

Justice Mumbi Ngugi, High Court of Kenya (Kenya)



Image: Justice Mumbi Ngugi giving the keynote address

Justice Mumbi Ngugi gave a keynote address entitled 'Five principles to guide the Nairobi Strategy Meeting in Mombasa, 2018.' The following is the address that she delivered verbatim:

'Good morning, ladies and gentlemen. Thank you for honouring me with the invitation to speak to you this morning at the start of our two days together. We have a lot to do in a relatively short two days, and we must make these two days' count. Each of us must have some ideas about how to move the very important strategy that we have committed ourselves to forward. However, allow me to take the opportunity, at this early stage, to set out five principles and propose that they must guide our time together over these two days.

First, as I believe we now all know, TB is one of the greatest humanitarian and human rights crises of our time. This is demonstrably true as an empirical matter. TB is the world's deadliest infectious disease. It takes at least 1.7 million lives a year. It is also true as a deeply personal matter. Those of you who know what it means to have TB or to endure the poison treatment for drug-resistant TB know that TB is most fundamentally a brutal affront to human dignity.

Second, an effective TB response must not only align to but indeed be born of human rights. Human rights should chart the course of the response to TB. They must be our true north if we are to win the war—and it is a war—against TB. And win we must. The first part of the work of this meeting must therefore be to continue to define the content of a human rights-based response to TB.

Third, we share an understanding that advocacy, mobilization, and the pursuit of legal redress for rights violations are tools to be used in this work. It is our legal frameworks that in large part determine how we will address this crisis. We must therefore be in touch and dialogue with the institutions that make, implement and interpret these frameworks: -our executive, legislative and judicial branches. This is the right and duty of citizenship. If the first part of our work involves defining the content of a human rights-based response to TB, then the second part of this meeting's work must be to strategize and plan how we will work individually and collectively to bring into being, make a reality, that which we envisioned in the first part.

Our different skills and positions enable us to do this. For lawyers and networks of people with TB, it means, for instance, identifying appropriate, strategic litigation to safeguard the rights of persons with TB, or to prevent continued/further violation of the human rights of persons with TB. For persons within the judiciary, it means the application of human rights principles to cases that come before us, as the court did in the case of Daniel Ngetich vs Attorney General. For those in the executive, it requires a response to the structural interdicts issued by the courts, not as a challenge to executive authority, but as an opportunity to work towards the betterment of the lives of citizens. This is, I believe, what the Ministry of Health in Kenya has done in formulating and launching the first ever National Tuberculosis Isolation policy on 26 June 2018.

Fourth, just as TB crosses borders so too must our response. TB demands a global response. We must work at the international level. Yet while recognizing this, we should reaffirm as well that the response must begin locally and rise upwards to collaboration at the international level. Our roots determine our strength and those roots must be in the communities we serve.

Fifth and finally, we must wage this fight as if it were a fight for our lives. Because it is. I invite the good people in this room to raise your hands if you or someone you love has been affected by TB.

This is why we must win. It is also why we can win.

This meeting is neither the beginning nor the end of our efforts. We operate in countries with different legal and policy frameworks, different cultures, different political realities. We have all made and missed targets. We have all won and lost battles. What brings us together is a belief in human rights and a desire to make them real in this world by applying them to the global TB crisis. Let this then be an opportunity to sharpen our swords and to strategize on how we will support one another as we work collectively and individually to respond to this crisis.

Let us then turn to the work that lies ahead of us. It is a lot of hard and challenging work, but we must approach it with new energy and old wisdom, knowing that it is not easy, but that we have the will and determination to confront it successfully. With that, I declare this meeting open. Let the work begin!'

DISTINGUISHED REMARKS FROM THE COMMUNITY:

Dean Lewis, Global Coalition of TB Activists, Touched by TB, International Network of People who Use Drugs & TB People (India)

Dean Lewis made distinguished remarks on behalf of communities affected by TB. Dean noted that TB and human rights was a fairly new concept, with the previous TB response not being keen on rights of patients. He noted that there had been some progress with concepts such as 'patient centred' and 'rights centred approaches' being incorporated in both local and global documents of the TB response. He however lamented the fact that the situation on the ground with regards to implementation was yet to embrace a rights-based approach.

Dean also noted that equal treatment of people in the TB response was lacking. He noted that most people were unaware of their rights, and effective mechanism for redress in case of violations were still lacking.

Dean advised on the need for capacity building of health care workers to respect rights of TB patients. Further, he noted that scientists working on developing medicines ought to appreciate the fact that they were making the same for human beings.

Dean gave examples of challenges faced by communities affected by TB including testing without consent, and lack of proper information. He noted that vulnerable community members – for example sex workers, drug users, and homeless people – were particularly disadvantaged in TB diagnosis, treatment and care.

Dean concluded his address by recommending empowerment of communities, documentation of rights violations, need to ensure access to food for communities affected by TB (not just nutrition), and access to free medication (not just affordable medication).



Blessina Kumar
@blessi_k



Gisa Dang
@xiaogi



@G_C_T_A Dean Lewis speaks passionately at the TB and Human Rights Consultation- 'In Human Rights, Rights are defined but what hasn't been is the 'human'! We don't need affordable medicines, we need free medicines.' @SpeakTB @StopTB @KELINKenya @acTBistas
09/08/2018, 11:14 from Shimo la Tewa, Kenya

5 Retweets 6 Likes

Yes! Understanding what your rights in TB prevention, diagnosis, and treatment under global WHO standards are is indispensable for fighting human rights violations.
treatmentactiongroup.org/content/know-y... #TBRights #righttoscience

SESSION ONE: Progress implementing the Nairobi TB Strategy (2016 – 2018)



Vivek Divan presenting the progress report of the Nairobi TB Strategy

Summary

This session aimed at sharing with participants about the *Nairobi TB Strategy* and the progress made in implementation. The session was chaired by Lynette Mabote, the *Regional Advocacy Team Leader at ARASA (South Africa)*. In the session, Brian Citro, a *Clinical Professor of Law, Northwestern Pritzker School of Law (USA)* took participants through the journey of formulation of the *Nairobi TB Strategy* and what the strategy entailed. Vivek Divan, an *Independent Consultant (India)* then shared the implementation status of the Strategy.

Remarks by session chair, Lynette Mabote (ARASA)

The Session Chair Lynette Mabote started by explaining that the purpose of the session was to review the implementation status of the *Nairobi TB Strategy* in detail. Lynette noted that the Strategy was a practical document and that it was a blueprint for implementation of human rights programmes in the TB response. Lynette then invited the session discussants Brian Citro - to give an overview of the *Nairobi TB Strategy* - and Vivek Divan – to discuss in detail the monitoring, evaluation and learning experience of the document.

Brian Citro: Overview of the *Nairobi TB Strategy*

Brian started by noting that the *Nairobi TB Strategy* had been helpful to the work on TB and human rights, and that whereas it was a global strategy it had supported activities both at the global, regional and local levels.

Brian also noted that the Strategy had provided an important opportunity to shape the narrative on TB and human rights. Further, that it had prioritized what needed to be done at both the global and local levels.

Brian shared that the workshop had been convened to review the progress in implementation of the *Strategy* and plan for the future. In this regard, it was expected that at the end of the workshop:

- (i) participants would develop a three-year costed work plan;
- (ii) participants would have shared what different organizations were doing;
- (iii) participants would have brainstormed on what was needed to be done, the resources required and how to raise the required resources;
- (iv) participants would have deliberated on creation of collaborations and partnerships in implementation of the *Strategy*.

Brian recounted how the *Nairobi TB Strategy* was developed. He noted that the *Strategy* was a product of the *Judicial Dialogue on TB and Human Rights* that was conducted in June 2016. And that the consultations with judges, lawyers, scientists, health care workers, activists, communities among others at the Judicial Dialogue gave rise to the *Nairobi TB Strategy*. Brian noted that there still existed an opportunity for improvement of the *Strategy* in terms of the language and the content.

Brian reported that a two-year progress report on implementation of the *Strategy* had been prepared; and that feedback on implementation progress was being collected through various means including online surveys.

Brian then concluded by taking participants through the *Strategy*, the overall goal, objectives and the activities under the strategy.

Progress report: The Nairobi Strategy: A human rights-based approach to tuberculosis - Vivek Divan

Vivek Divan started by sharing the core components of the *Nairobi TB Strategy* as follows:

- (a) Empower and Support networks of affected communities of people with TB, survivors and broader civil society at global, regional and national levels;
- (b) Enhance judiciary and legal communities' awareness on implementation of a human rights-based approach to TB;
- (c) Expand legislators' and policymakers' capacity to incorporate human rights-based approaches to TB into laws and policies;
- (d) Engage and advise international organizations and experts on the implementation of human rights-based approach to TB into global policies and programmes;
- (e) Sensitize healthcare workers in public and private sectors on the need to incorporate a human rights-based approach to TB in their work;
- (f) Formulate and clarify the conceptual, legal and normative content of a human rights-based approach to TB;

- (g) Conduct qualitative and quantitative research to generate evidence base for the effectiveness of a human rights-based approach to TB; and
- (h) Facilitate inclusive, community-led discussions to develop and promote use of ethical standards to gather and use TB data

Vivek shared the progress made on the various components as follows:

As regards to **community empowerment**, Vivek noted that implementation was both at the international, regional, national and local levels. Vivek gave an example of the *Stop Stock outs Project* in South Africa that was monitoring and making health system accountable through empowered communities. The main challenge was that TB was not seen as a rights issue and that there was tokenism at policy level.

As regards to **judicial and lawyers' capacities**, it was reported that there had been:

- Publications – case law compendium, judicial handbook;
- Trainings – e.g. the African Regional Judges Forum, HIV, TB and criminalization for training for lawyers, among others.
- Litigation – reported in South Africa, India, Kenya.

The main challenges in this regard revolved around ensuring sustained education of judges and limited funding for legal aid work.

As regards to **legislators and policy maker's engagement**, the Global TB Caucus was identified as an opportunity.

Further, that in regards to **rights-based law reform**, there was progress in development of notification & isolation standards, for example in Kenya following the *TB is not a crime case*. Relatedly, legal environment assessments of TB had been conducted in several countries (Kenya, Nigeria, Tanzania, Cambodia, India, etc.). The main challenge reported here included lack of sufficient data to canvas for reform.

With regards to **engaging and advising international organizations**, it was reported that the *Strategy* had contributed to the following processes:

- supplement to the report of the Global Commission on HIV & the Law
- information to the Special Rapporteur on the Right to Health
- contributed to the process leading to the UN HLM on TB
- information to shape the WHO Ethics Guidance to Implement the End TB Strategy.

The main challenge in this aspect revolved around mobilizing donors to support the process but an opportunity existed in creation of awareness of civil society to use available mechanisms (for example, opportunities presented by the Global Fund).

With regards to **capacity building of healthcare care workers**, it was reported that the following had been accomplished:

- Know Your Rights brochure developed by the Chicago Department of Public Health and Northwestern University School of Law;
- Trainings on law and rights;
- Patients Charter was in the process of review.

The main challenge reported was the fact that TB is highly medicalized and that there was a challenge in overcoming attitudinal issues of health care workers.

In relation to **evidence and scholarship**, it was reported that the following had been accomplished:

- The *Human Rights & Health Journal* dedicated an issue on TB and rights;
- The International Journal of Tuberculosis and Lung Disease has had many recent publications on TB/ law/ human rights;
- TB Stigma Measurement Guidance was being developed by USAID.

The main challenge was the fact that more research was needed and the need for funding for the same.

Plenary session

In the plenary session, the following questions and issues were discussed:

- Some participants wanted to know whether the online survey for feedback on the progress in implementation of the *Nairobi TB Strategy* would be shared with a wider audience. In response, it was noted that indeed wider consultations for feedback would be done.
- Some participants noted that there were some issues that had been reported as part of the *Strategy* but preceded the *Strategy*, but that they were important to build networks and enhance partnerships. For example, it was noted that the African judges' regional forum was not directly linked to the *Nairobi TB Strategy*. However, that there was need for judges to understand issues around TB and human rights.
- A participant explained the opportunity presented by the Global TB Caucus. The participant noted that the Caucus was a group of parliamentarians that had come together to advance the course of TB and human rights. It was noted that they provided a good opportunity for partnership given that they had powers to legislate in their respective countries. And that the engagement of legislators needed to be regular given the changes that occur in parliaments at regular intervals.

- Participants also suggested the need to hold some international organizations to account – especially those accused of human rights violations of people affected by TB. And that the TB response in relation to human rights must transcend borders.
- Some participants wanted to know how governments could mainstream human rights in health systems. In response it was noted that conversations on health systems should be viewed more broadly, and that in setting up and implementation of the systems human rights considered at all stages.
- There was an opinion that most governments still focused on biomedical aspects of TB at the expense of human rights.
- It was also noted that *Nairobi TB Strategy* was focused and aimed at addressing issues of TB, human rights and the law which was commendable.

SESSION TWO: Documents for input and feedback

Summary

This Session aimed at interrogating three crucial documents that are in the process of development in implementation of the *Nairobi TB Strategy*. These were:

- The *Declaration on the Rights and Responsibilities of People with TB (revised Patients' Charter for Tuberculosis Care)*. Discussion on this document was led by Timur Abdullaev of *TB People* (Uzbekistan);
- The *Judicial Handbook on TB, Human Rights and the Law*. This was presented by Brian Citro, *Clinical Professor of Law, Northwestern Pritzker School of Law* (USA);
- *TB in Prisons: An introduction to the law* presented by John Stephens, *The O'Neil Institute* (USA).

The session was chaired by Allan Maleche, *Executive Director, KELIN* (Kenya)

TB in Prisons: An introduction to the law - John Stephens

In explaining what informed the development of this guide, John Stephens noted that there were challenges in the funding scenario for TB and human rights. This therefore greatly affected programmes on legal empowerment.

John noted that the guide was thus developed out of the need to empower communities and activists with legal knowledge and knowledge of rights for them to be self-advocates. He stated that it was important for different actors to play their role in the TB response, and if communities and TB patients are empowered then they would be in a better position to demand for rights.

John noted that the guide was about TB in prisons, gave basics on the law, easy to ready and to use by communities and activists. And that the guide was not about the law in one specific country, but explained basic legal principles as well as the basic infrastructure of law. The guide also gives helpful tricks to help activists be confident when they use the law in their campaigns. The guide would empower TB activists understand and use the law at a general level.

Judicial Handbook on TB, Human Rights and the Law - Brian Citro

Brian noted that the *Judicial Handbook on TB, Human Rights and the Law* was a tool meant to sensitize judges and judicial officers on TB.

He noted that the handbook had Chapters that dealt with:

- The Science and Medicine of TB to provide a basic understanding of medical aspects of TB;
- The legal and public aspects of TB, that is TB, human rights and the law. And that this section reviewed what the human rights standards are, the legal issues and challenges faced by communities affected by TB, implications of the legal challenges, case law, and some comparative analysis.

Brian noted that the Handbook has reviewed TB issues in education, employment, immigration, prisons, and issues as pertaining to key populations (health care workers, children, prisoners, mobile populations, urban and rural poor, people who use drugs, mine workers, people living with HIV and women).

Brian noted that the *handbook* was specifically written to judges and the judiciary and hoped to get input from participants on its content. He also hoped to interest participants to contribute to chapter review of the handbook to ensure that it is fully owned by stakeholders.



John Stephens (left) and Brian Citro presenting on the TB in Prisons: An introduction to the law and the Judicial Handbook on TB, Human Rights and the Law, respectively.

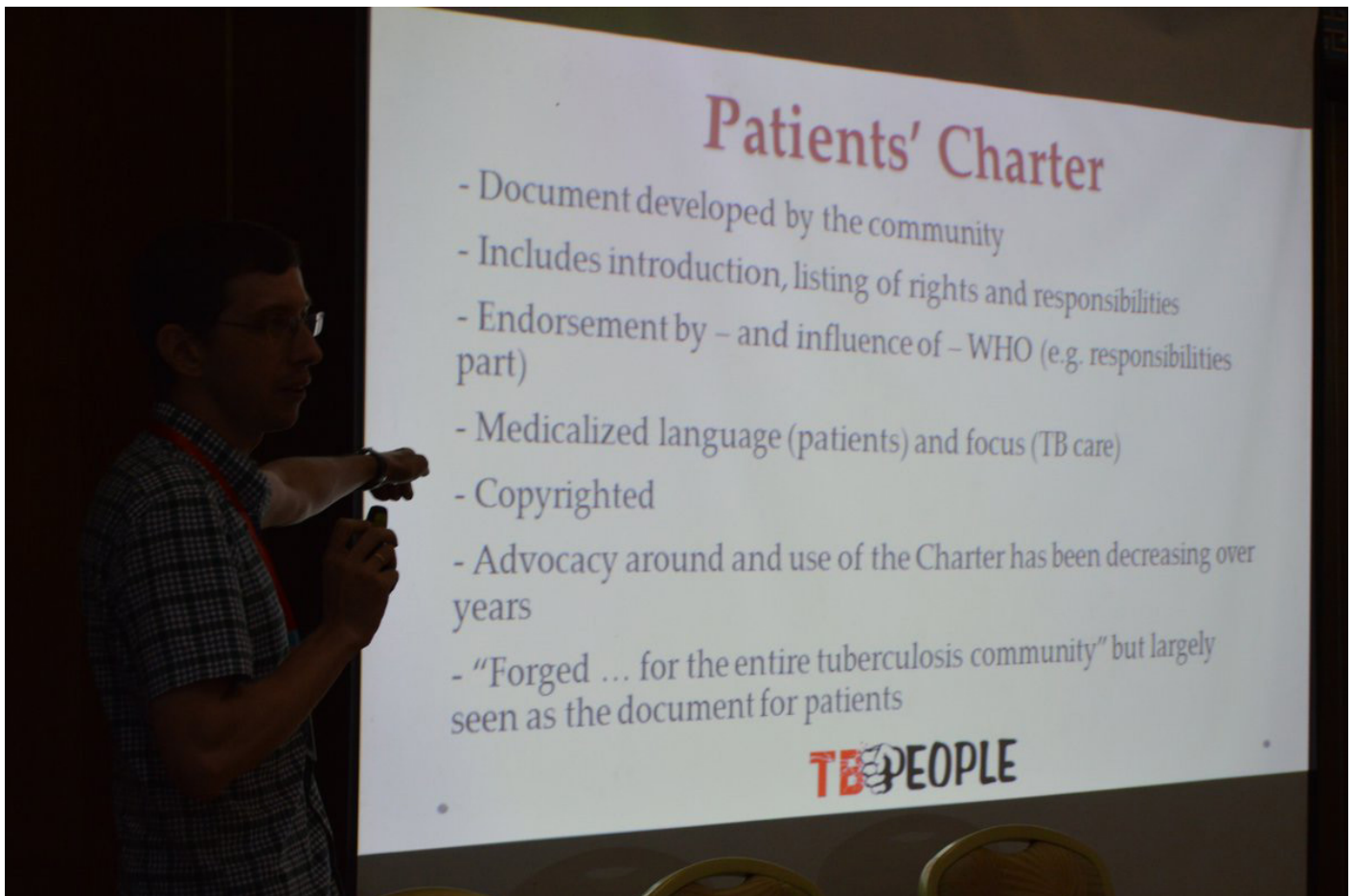


Image: Timur Abdullaev making a presentation on Declaration on the Rights and Responsibilities of People with TB

Timur Abdullaev presented on the *Declaration on the Rights and Responsibilities of People with TB*. Timur started by giving a history of the Patients' Charter by noting that it had been developed by a group of activists and published in 2006. The Charter was translated into several languages and led to the adoption of national patients' charters. Further, that for several years, various groups have voiced the need to revise the Patients' Charter.

Timur noted that in 2017 a first consultation was held on development of a new document, tentatively called 'Declaration of the Rights and Responsibilities of People with TB' leading to the development of a 'zero' draft which was then being presented at this workshop.

Timur first discussed what was contained in the 2006 Patients' Charter. He noted that although it had been developed by the community, the World Health Organisation had also endorsed and influenced contents of the Charter such as the section on responsibilities. The Charter was also to some extent written in a medicalized language, focused on medical aspects, was copyrighted, and that advocacy around and use of the Charter, had been decreasing over years. Further that it was largely seen as a document for patients as opposed to the entire tuberculosis community.

Timur then stated that the *Declaration on the Rights and Responsibilities of People with TB* which was still in zero draft was being developed with the following vision:

- Process: global community-driven development
- Language: from 'patients' to 'people'
- Focus: from 'TB care' to 'TB responses'
- Wider consultations on whether responsibilities needed
- More aligned to international human rights standards
- More comprehensive and explicit
- A tool for empowerment, capacity building and advocacy
- Endorsement/support from a broader TB and health community
- Not copyrighted

Plenary session

- In the plenary, participants appreciated the presentations noting the documents were indeed crucial in the TB response. The different cadre of participants were advised to interrogate the documents, for example, activists to scrutinize whether community issues had been articulated; health care workers and scientists to scrutinize how medical issues had been captured, among others.
- Participants wanted to know how the Judicial Handbook could be used by organizations involved in advocacy at the community level. In response, it was noted that the judicial handbook could be used in advocacy and capacity building with communities. It was however noted that there might be need to tailor it for different contexts.
- Regarding the Patients' Charter, it was noted that there had been a 2015 process that had been started but stalled due to lack of funding. It was noted that it would be important to recognize what had been done – and foster the need for inclusivity and bringing together all stakeholders. Participants advised on the need recognize what was already happening and building on the process rather than creating new content. In response, it was appreciated that indeed the previous process on the Patients' Charter was important since a lot of work had been done. It was noted that the Declaration, still at draft zero, would continue and build upon the Patient's Charter and previous attempts at revision. It was also noted that the Declaration was revisiting what had been done to make improvements.
- Participants also wanted to know whether the Judicial Handbook captured research and development components. In response, it was noted that chapter five of the Handbook had a session on access to new drugs and new medicines. It was however noted that there might be need to include some scientific information for communities and a section on international law.

- Participants wanted to know the possibility of developing one document with all the components. In response, participants were advised to view the three documents as part of one strategy.
- A participant advised on the need to include special provisions for children in the Declaration of Rights and Responsibilities.
- Participants wanted to know how the handbook addressed issues of confidentiality in writing of judgments. In response, it was noted that indeed such a session was useful and would be included.
- Participants suggested the need for inclusion of list of referrals to legal services in the Judicial Handbook.
- Participants also advised the need for inclusion of issues of universal health coverage and SDGs in the handbook.
- Participants were also keen on knowing the implementation plan for the documents. They suggested the need to develop an implementation plan and tracking mechanism by communities.
- Some participants wanted to know whether a model law on TB would be developed. It was noted that opinion was mixed on whether it was a good idea – given that the experience with HIV laws was also mixed.

In concluding the session, the chair Allan noted that there was indeed interest on the documents and that three important issues had emerged during the plenary as follows:

- The need for harmonization with previous processes;
- The need to make the documents relevant to and for use by communities; and
- The need for inclusion of an implementation plan.

SESSION THREE: Group work: Feedback on draft documents and presentation of group recommendations

Summary

This was a group session where participants interrogated the three documents, that is,

- Declaration on the Rights and Responsibilities of People with TB (revised Patients' Charter for Tuberculosis Care);
- Judicial Handbook on TB, Human Rights and the Law; and
- TB in Prisons: An introduction to the law.

Participants discussed the documents using the following guide:

Group Discussions Guide

1. Could this be useful to your work?
2. How would you use it and what would we need to do so?
3. Is there something critical missing from the document that you would like to see?
4. Once this document is finalized, how and who should be involved in its dissemination and implementation?

Northwestern
PRITZKER SCHOOL OF LAW
Bluhm Legal Clinic

Stop TB Partnership

 **KELIN**
Reclaiming Rights, Rebuilding Lives

GROUP 1: Judicial Handbook on TB, Human Rights and the Law

- The group reviewing the Judicial Handbook reported that the handbook was developed for specific audience but should also be tailor-made to be useful to community members and activists.

- They appreciated that the Handbook would be important to judges as they make their decisions but could also be used by lawyers in developing legal arguments relating to TB and human rights.
- Further, they noted that the Handbook could also be useful in strategic litigation, submissions for policy and legislative change and by national human rights institutions in the course of their work.
- The group reported that they would like to see issues of accountability addressed in the handbook; inclusion of more case studies; an introduction on why the handbook is necessary; a section on ethics in conducting research on people with TB; customization of key populations and TB issues in migration.
- The group reported that the following should be involved in dissemination and implementation of the handbook, among others:
 - The Global TB Caucus
 - Africa Regional Judges Forum
 - Judicial Training Institutes
 - Parliaments
 - International organizations and development partners like IDLO, UNDP, Stop TB, OCHR, among others
 - National TB Programmes
 - Universities and academic institutions
 - Civil societies and communities affected by TB

GROUP 2: Declaration on the Rights and Responsibilities of People with TB

- The Group reported that the *Declaration on the Rights and Responsibilities of People with TB* would be useful in advocacy, capacity building and empowerment.
- The group further made the following recommendations:
 - The need for broader consultation on the name of the document (declaration?)
 - Inclusion of guiding principles
 - Consultation on whether responsibilities should be included
 - A careful examination of the language used in the declaration
 - The document to address issues of key populations including children, people living with HIV, mobile populations among others

- The need to ask for an enabling environment
- The need to ensure the document is not used against people affected by TB in the long run
- Include issues of disabilities caused by TB treatment – given that that they have lifelong impact
- Include right to science from various international conventions and community participation in research
- Include responsibilities of government
- Include an accountability framework and implementation framework
- The group also suggested the need for the next steps to be clearly laid down for a more inclusive process.

GROUP 3: TB in Prisons: An introduction to the law

- The Group suggested that the document should also specifically target health care workers and physicians who have little legal knowledge.
- The group asked the authors to also address issues to deal with accountability – for example who is responsible if a health care worker prescribes medication and it is not available.
- The Group noted that the document was important in providing information on prison setting hierarchy thereby ensuring requests were escalated quickly.
- The group suggested that the document addresses some terminology issues, for example, people in prison who have not been convicted, what sentencing means, among others.
- The group also suggested an interrogation of who has the responsibility to reintegrate people released from prison to the community.
- The group noted that it was an informative tool to evaluate reasons why one cannot refer a person to prison for failing to take their medication.
- Further that the document could also review issues of access to services by prisoners, especially in relation to research and development.
- The group suggested that in dissemination and implementation, health care workers should be involved; and CSOs for advocacy.
- The group however suggested that there might be need to train CSOs on dissemination and implementation of this guide.



Dr Stellah Bosire (right) and Dr Jennifer Furin taking part in group discussions

SESSION FOUR: Testing and treatment justice: Access to new drugs and diagnostics for all

Summary

This session aimed at interrogating measures to achieve testing and treatment justice for people affected by TB. The session discussant Dr Jennifer Furin, *Lecturer on Global Health and Social Medicine, Harvard Medical School and DR-TB Training Network, USAID (USA)* discussed issues pertaining to new diagnostics, progress in research, new medication, access to drugs and related issues.

During the session, participants also watched a video meant at showing the practical challenges faced by people affected by TB in the community. The session was chaired by Tendai Mafuma, a *Researcher at SECTION27 (South Africa)*.



Dr Jennifer Furin discussing issues relating to advances and access to TB science.

Dr Furin started by sharing that TB science was at an exciting moment since:

- Science of TB was blossoming leading to a number of important innovations in the field. However, that access to these innovations had not kept pace with the need for them: and that most people were unable to benefit under the current TB structures. And that this was despite the fact that the WHO ethical guidance emphasized the right to health, the right to benefit from science, and the importance of timeline-driven progressive realization.

In relation to TB diagnosis, Dr Furin gave an example of a lifesaving test, TB LAM, whose access was not offered in most settings. This was despite the test having the following advantages:

- It is point of care, rule-in test that detects TB proteins in the urine;
- Most beneficial in people living with HIV who have CD4 counts < 200 cells/uL;
- Only diagnostic test associated with reduction in mortality;
- Cost-effective

In relation to TB Treatment, Dr Furin cited the case of Injectable-Free Regimens for DR-TB whose access was still a major concern and their costs too high. This was also despite the fact that there was increasing evidence on the efficacy and safety of the newer and repurposed drugs (bedaquiline, delamanid, linezolid). Further there was continued and growing evidence on the harms and ineffectiveness of commonly used drugs (injectable, PAS, Ethionamide) – ‘Treatment being worse than the disease’.

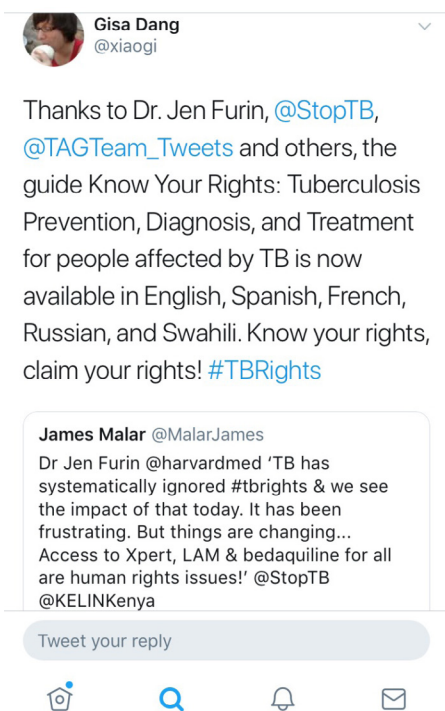
In relation to TB Prevention, Dr Furin noted that there were Shorter, Safer Regimens for Treating TB Infection as follows: twelve-week regimen of once-weekly INH and RPT; four-week regimen of daily INH and RPT; and four-month regimen of rifampin. However, that only less than 10% people receive treatment of TBI, and that there were different standards for wealthy and poor countries advocated by WHO.

Dr Furin noted that as of then *End TB* was just a Slogan (but it didn’t have to be....) if the following were addressed:

- Accountability framework was essential (but missing....);
- Catch phrases (i.e. ‘human rights-based approach’, ‘people centred care’) must be coupled with consequences for programmes, providers, policy makers and ‘payers’ if not followed;
- International ‘high-level’ meetings alone would not solve the problems of people on the ground;
- Activism and advocacy based on strong collaboration poised for great success

Dr Furin finalized her presentation by sharing a story of a TB patient in South Africa who was failed by the health system leading to death. That in the course of treatment the patient developed multiple side effects (deafness etc.) as a result of the medication.

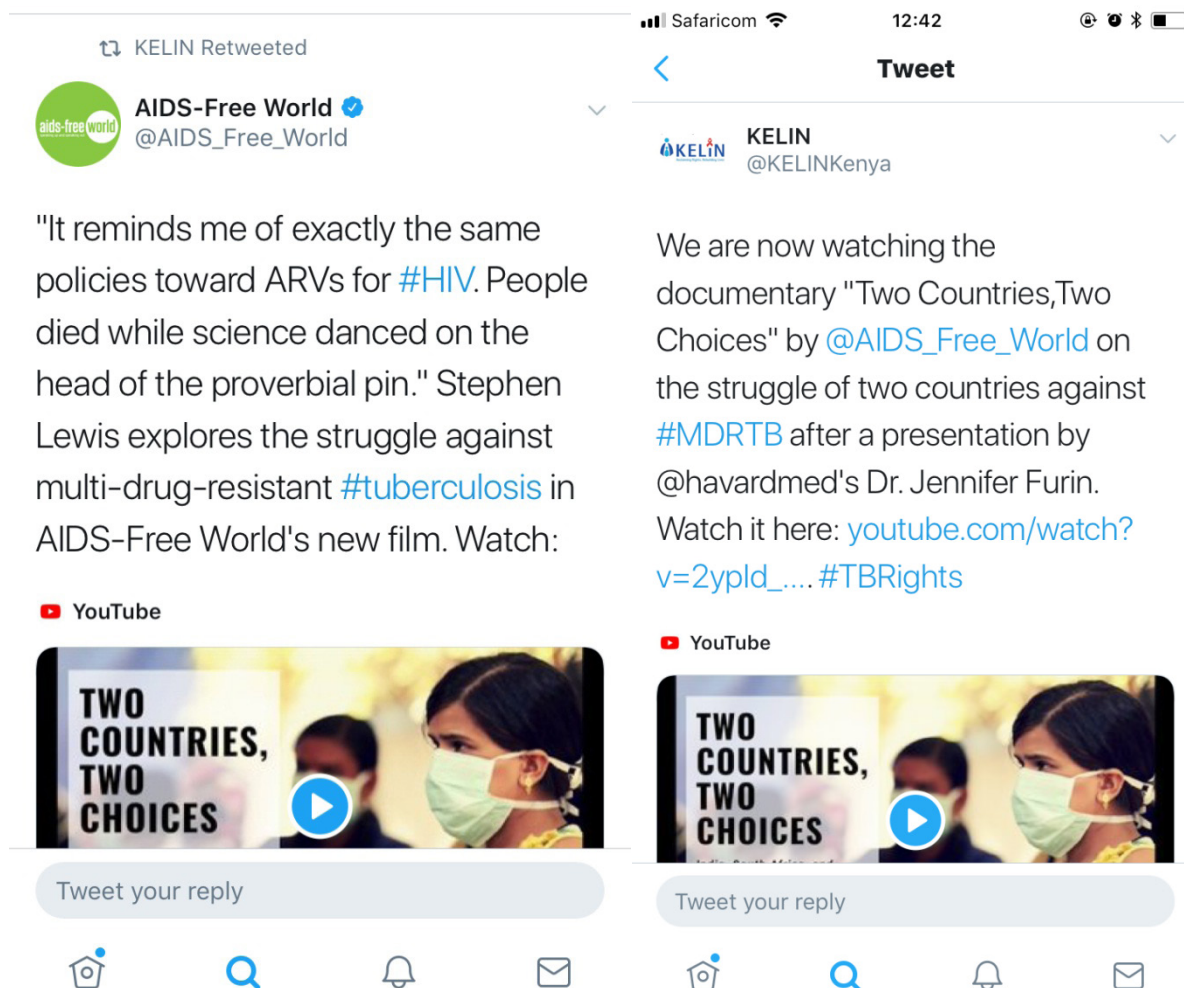
Dr Furin concluded by noting that there was need to say goodbye to the public health approach to TB because it has not worked. ‘It failed us.’



Video: 'Two Countries, Two Choices' – AIDS Free World

Participants then had an opportunity to watch a documentary film by AIDS-Free World – “*Two Countries, Two Choices: India, South Africa and the Struggle against Multi-Drug-Resistant Tuberculosis.*”

The documentary the challenges faced by people affected by TB focusing on access to Bedaquiline and Delamanid drugs for MDR-TB patients in India and South Africa.



Plenary session

During the plenary session, participants had the following reflections:

- That there was need to ensure entire health systems were interrogated to ensure access to diagnosis, treatment and care;
- Some participants wanted to know why the TB LAM test was not widely used. In response it was noted this was due to its cost and since it was not 'a perfect test.'
- It was also noted that the LAM test had mostly been recommended for PLHIV.

- Some participants wanted to know the progress on research on TB vaccines. In response it was noted that TB clinical trials took an average of 10 years and that TB research had stagnated mainly due to lack of investment.
- It was also noted that Bedaquiline and Delamanid had been shown to be effective; however, the innovation was not being used. And that there was need for communities to advocate for utilization of this innovation and for new innovations. Communities were also urged to demand from responsible agencies why these drugs were not available and accessible.

CLOSING REFLECTIONS

Blessina Kumar, CEO, Global Coalition of TB Activists (India)

In making closing reflections, Blessina Kumar of *the Global Coalition of TB Activists* noted that activism on TB rights had been a lonely battle with little support forthcoming. Blessina remarked that the TB community was yet to be empowered to demand for their rights. Blessina called on partners to invest in communities as a fall back mechanism to create demand. She called for the TB movement to be led by affected people to avoid a scenario of tokenism.

Blessina noted that there was need to ensure that the messaging for core minimum demand for people affected by TB was clearly communicated: that is, people needed access to safe and quality drugs; and rights of people ought to be respected.

Blessina urged communities to speak with one language and not just for the upcoming UN HLM on TB. That all efforts should lead towards ensuring a people centred approach was embraced in totality.

DAY TWO: 10 August 2018

INTRODUCTION AND FRAMING THE CONVERSATION: Brian Citro

The second day of the workshop started with Brian Citro framing the conversation for the day. Brian noted that the day was dedicated towards interrogating the following:

- Actions to further develop and implement the *Nairobi TB Strategy*; and
- Ideas and reflections to move forward.

Brian remarked that indeed there was no demand in TB and human rights hence the need for more visibility and to ask for more resources to take the work forward.

Participants had been asked the previous day to reflect on the future of the Nairobi Strategy and the priority areas going forward. Specifically, participants had been asked to:

- Share one piece of work/project they wanted to build on, or support, or new idea they wanted to undertake after the discussions on TB and Human Rights;
- Share the resources they needed (financial/technical/collaborations/new strategies) to advance the existing and new work on TB and human rights?

Brian used this session to read out some of the reflections from participants as summarized below:

- Develop modules for training TB treatment literacy for the global community that is rights based
- Develop the declaration on rights and responsibilities
- Help with the chapter on engaging the judiciary in the Judicial Handbook
- Build the capacity of CSOs on TB in prisons
- Conduct legal environmental assessment and would need technical and financial assistance to conduct the TB LEA and to reach out to affected communities
- Help coordinate and mobilize and share experiences on TB and human rights.
- Empowering TB champions and use the media in talking about TB.
- Help activists or organizations who want to do strategic litigation or use law in campaigns
- Build advocacy networks nationally, regionally and globally and ensure that there was coordination with lawyers, judges etc. under Nairobi Strategy
- Advocate for enablers for TB patients (nutrition, social security)
- Probing for better data collection and use

KEYNOTE ADDRESS: Justice Edwin Cameron, Constitutional Court of South Africa (South Africa)



Image: participants listening to the keynote address by Justice Edwin Cameron

Justice Edwin Cameron of the Constitutional Court of South Africa gave a keynote address via video link. Justice Cameron started with encouragement to participants at the meeting. He noted that he is a person living with HIV having been infected 33 years ago and diagnosed 32 years ago. Justice Cameron noted that 21 years ago he fell severely ill with AIDS but was able to reclaim his health, strength and life through the use of antiretroviral therapy (ART). He however noted that he was only able to access treatment at the time because he had the resources and could thus afford.

Justice Cameron remarked that the situation was now different with massive public funded treatment programmes for HIV treatment. And that the current situation was not a gift but was fought for.

Justice Cameron hailed the Nairobi Strategy particularly as it emphasized several aspects on how to deal with TB. Justice Cameron urged all to pause and recognize the ferocity of TB and deaths it caused. Justice Cameron particularly stresses two aspects of the Nairobi Strategy that he was grateful for:

- First, the need for those affected by TB to be involved, their views heard, respected and considered. He decried the silence of the affected which was mostly caused by stigma.
- Second, the need to embrace human rights-based approaches. Justice Cameron noted that public health approaches to disease management had largely been counterproductive and catastrophic. He cited the case of medicalization, criminalization and the authoritarian approach to HIV which didn't work leading to the embrace of human rights-based approaches. He urged involvement of all populations including the marginalized, vulnerable and underserved to achieve sound, sensible, just and effective approach to the TB response.

Justice Cameron concluded by noting that TB treatment was agonizingly difficult hence the need for affected communities to speak up about this, the side effects and advocate for further and better scientific research on the same.

DISTINGUISHED REMARKS FROM THE COMMUNITY: Timpiyan Leseni, Founder Talaku, (Kenya)



Image: Timpiyan Leseni giving distinguished remarks at the workshop.

In her distinguished remarks, Timpiyan shared her personal journey as a TB patient. She noted that in 2011 she suddenly started losing weight, having night sweats and her stomach swelling. She noted that she sought medical attention where a mass was removed from her stomach – however no sample was taken to the laboratory for testing. She was put on antibiotics but her situation continued getting worse.

She went back to a different hospital where another operation was done and puss removed from her body. It was then that she was diagnosed with TB of the intestines. She was informed that it could have come from animal products. She was then put on medication for seven months with one month of injections. Timpiyan reported that the medication was too tough, tablet big, and with many side effects. She persevered until she was completely cured.

Timpiyan reported that her experience inspired her to start going back to health facilities to help other patients – and educating them on need to take medication.

Timpiyan stated the experience had made her become an active TB activist working on community empowerment, fighting stigma and discrimination. She noted that there were so many challenges at health facilities necessitating the need for provision of proper information, sensitization of TB communities, and programmes to fight stigma.

Timpiyan concluded by noting that it was no longer tenable just to provide nutrition supplements, affected families need food.

SESSION FIVE: Talk Show: What's happening in TB and human rights? A discussion with people on the frontline

Summary

This session aimed at sharing with participants what was happening in relation to TB and human rights. The session discussants, being people on the frontline, shared their various initiatives and contribution to the TB and human rights agenda. The Session was chaired by Alberto Colorado, an International Public Health Consultant, (USA) with discussants being:

- Priyam Lizmary Cherian, Legal Officer, Lawyers Collective (India)
- Gisa Dang, Consultant, Treatment Action Group (USA)
- Dr Eunice Mailu, National TB Programme, (Kenya)
- James Malar, Community, Rights and Gender Advisor, Stop TB Partnership (Geneva)
- Evaline Kibuchi, Stop TB Partnership (Kenya)



Image: Left to right – Gisa Dang, James Malar, Alberto Colorado, Eunice Mailu, Priyam Lizmary and Evaline Kibuchi during the talk show session

Gisa Dang, Consultant, Treatment Action Group (USA)

Gisa Dang discussed Treatment Action Group’s research in relation to the right to science. Gisa noted her team reviewed how human rights apply to TB and then delved in to the right to science. Gisa noted that the right to science was found in several international conventions including Article 15 of the International Covenant on Economic, Social and Cultural Rights

Gisa shared that the right to science was a great tool to talk about and was described in full as the *right to everyone to enjoy benefits of scientific progress and invention*. Gisa remarked that governments had certain obligations and responsibilities as pertains to the right to science including, to observe, to develop, to diffuse (share) science and encourage international cooperation.

Gisa pointed out the right of participation in science for communities – that is - access to scientific knowledge, information and the products.

Gisa concluded by introducing resources developed by Treatment Action Group on how human rights and the right to science belong together. The resource *‘Know Your Rights: Tuberculosis Prevention, Diagnosis, and Treatment Guide’* notes in summary that:

- Every person must benefit from science;
- Government should support science, and research;
- Right to science includes right to participation of communities in respectful manner;

Gisa noted the need to use testimonies to analyze what was needed, the human rights issues affecting access, for example, use of outdated medication, lack to access, discrimination and bringing all these to the attention of UN.

Gisa concluded by noting the UN was coming up with a General Comment on right to science and that TAG would want to organize communities to comment on the contents of the General Comment.

James Malar, Community, Rights and Gender Advisor, Stop TB Partnership (Geneva)

James Malar of Stop TB Partnership (Geneva) shared on the tools developed by Stop TB to advance TB and human rights work.

James noted that Stop TB had developed three tools being:

- Legal Environment Assessment for Tuberculosis
- Gender Assessment Tool for National HIV and TB responses
- Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations

James noted that this showed progress in shaping the narrative on TB and human rights and understanding the barriers.

He noted that these tools in place had led to:

- review of laws, policies, and operational frameworks;
- engagement with communities on how these policies impact on them
- engagement with National TB programmes and bringing together of different stakeholders
- provision of evidence-based responses
- creation of working multi-sectoral relationships
- Community monitoring and social accountability tool piloted in Kazakhstan to build community support networks

He concluded by noting that there was gradual change and increased levels of investment for communities.

Eunice Mailu: National TB Programme (Kenya)

Eunice shared that Kenya had developed a TB Isolation Policy and that she would share on the experience in its development and the implementation plan. Eunice noted that the Isolation Policy was as a result of guidance from the *Daniel Ngetich & Others versus Attorney General and Others* where Justice Mumbi Ngugi directed that such a policy be put in place. Eunice shared that the TB Programme took the judgment positively and formed a taskforce that developed the isolation policy.

Eunice stated that the policy would guide the treatment of patients in need of isolation while ensuring that their rights were respected. Eunice noted that the policy also included structural designs for isolation wards and had been developed in collaboration with county governments, civil societies, communities, development partners and other government agencies (for example the office of the Attorney General).

Eunice noted that counties were responsible for the implementation of the policy with some already making budgetary allocations for the same.

Eunice also shared that the recommendations of the Legal Environment Assessment of TB, Gender and Data Assessments conducted in Kenya had been of great use to the TB programme especially as they developed their Strategic Plan. She noted that the reports helped point out gaps, and that they had already been used to develop indicators for TB key, vulnerable and underserved populations in the M&E frameworks.

Priyam Lizmary Cherian, Legal Officer, Lawyers Collective (India)

Priyam shared the experience of Lawyers Collective in India in fighting for the right of a TB patient to access TB medication – Bedaquiline.

Priyam noted that Bedaquiline was then only available in certain regions of India. An MDR TB patient tried to access in another region but was unable to. The patient travelled to a region where it was available but was refused the medication due to the fact that the patient originated from another region.

Lawyers Collective filed a petition in court which the government opposed citing the reason that the drug was not yet approved. However, the government eventually provided the medication and the petition settled by consent. Priyam concluded that Lawyers Collective worked in fighting patent monopoly to ensure access to medicines.

Evaline Kibuchi, Stop TB Partnership (Kenya)

Evaline Kibuchi discussed Stop TB Kenya's work on TB politics and engagement with politicians through the parliamentary TB Caucus. Evaline noted that the Parliamentary TB caucus was established to respond to the problem of low political commitment in TB.

She noted that the Global TB caucus was a group of parliamentarians whose sole goal was to advocate for TB and that 135 countries were represented. Evaline noted that the caucus was established when over 2000 members of parliament signed the Barcelona Declaration and committed to work in their capacities to address TB in their countries. She shared some of the achievements of the caucus as:

- Ensured TB was recognized in G20 heads of state meeting;
- Have been instrumental in preparation for the UN HLM on TB through ensuring their head of states attend;
- Called for increased funding for R&D;
- Participated in development of end TB strategy;
- Have been key in allocation of budget to TB.

In conclusion Evaline recommended the need to engage and involve parliamentarians regularly and from beginning.

SESSION SIX: Roundtable: What next for the draft Political Declaration for the UN High-Level Meeting on TB?

Summary

This session aimed at interrogating the upcoming UN High Level Meeting on TB. The session discussants provided opinion of what should be done to ensure the political declaration that comes out of the UN HLM was impactful to the TB response. The session was chaired by Elvi Siahaan the Country Director of Yayasan MAP Internasional (Indonesia) with the discussants being:

- Dean Lewis, Global Coalition of TB Activists, Touched by TB, International Network of People who Uses Drugs & TB People (India)
- John Stephens, The O'Neil Institute (USA)
- Austin Obifuna, Executive Director, Afro Global Alliance (Ghana)

Dean Lewis, Global Coalition of TB Activists, Touched by TB, International Network of People who Uses Drugs & TB People (India)

Dean shared his disappointment about the Political Declaration Statement for the UN High Level Meeting on TB. He noted that many issues had been avoided and that advocacy was still needed.

He expressed disappointment on the lack of an independent accountability mechanism in the political declaration thus effectively giving WHO the power to account to themselves.

Dean noted that communities had asked for rights which were not fully included thus meaning that there was a possibility of not getting the declaration that was wanted. That there were asks on a 9-member committee hosted independently of the WHO but this wasn't included.

Austin Obifuna, Executive Director, Afro Global Alliance (Ghana)

Austin Obifuna shared that the UNHLM on TB was an opportunity to put TB on the global map. And that it had already generated discussions on TB. He agreed that the day would be an event but that the process before and after had potential to shape the discussion on TB. He noted the need to ensure advocacy for countries to adhere to the commitments.

Austin recommended that the message from the HLM is passed to communities. He also recommended that position papers on issues not included be developed and strategically distributed at the HLM.

Austin was positive given that this was the last HLM on an individual disease by the UN.

John Stephens, The O'Neil Institute (USA)

John Stephens shared about a petition that had been drafted with specific demand especially the need to include a statement on use of TRIPS flexibilities to achieve the right to health.

John called upon stakeholders to review and sign on to the letter and support in the distribution process. He noted the need for CSOs to work as a team, take out their mandate as a watch dog on the public sector to ensure good health systems.

The letter was later reviewed by participants, input incorporated and adopted as the official communiqué from the workshop to the UN HLM on TB. The communiqué can be accessed here: A communiqué issued from delegates convened under the umbrella of the Nairobi Strategy on Tuberculosis and Human Rights

Plenary session

Participants made the following reflections during the plenary session:

- There was need to use official delegations for further advocacy in the UN HLM process;
- The need to appreciate the fact that the declaration might not be perfect but advocate to have it as good as possible;
- CSOs need to be active to push forward the agenda;
- The UN HLM was a significant event and it was important that CSOs and communities continue with advocacy until the last minute – not to lose momentum;
- Participants were urged to support the letter drafted through signing on it. It was also noted that there was a lot in the political declaration that could be used but that it would 'not be a good strategy' not to demand more;

SESSION SEVEN: Group work: Prioritization of activities under the Nairobi TB Strategy

Strategy Chairs: John Stephens, *The O'Neil Institute (USA)* & Tendai Mafuma, *Researcher,*

SECTION27 (South Africa)

In this session, participants developed work plans from the Nairobi TB Strategy on what they intended to undertake in the next three years. (These are as annexed to this report).

PLANNING THE NEXT STEPS: Strategy session to advance a human rights based-approach to TB

Chairs: Brian Citro, *Clinical Professor of Law, Northwestern Pritzker School of Law (USA)* and Allan Maleche, *Executive Director, KELIN (Kenya)*

In this Session, Brian Citro and Allan Maleche led in reviewing what had been achieved in the meeting. They reported as follows:

- (a) The meeting had hoped to measure progress in implementation of the Nairobi TB Strategy. In this regard, feedback had been provided to the evaluation report which was still in draft form.

Brian and Allan reported that the consultant, Vivek, would continue to gather feedback from both participants at the meeting and a wider audience. The progress report would then be finalized and shared.

It was reported that the purpose of the progress report was not just for record purposes but to demonstrate to donors what had been achieved with little resources. It would also outline what needs to be supported and the next steps.

- (b) The meeting had also hoped to have participants develop work plans. It was reported that this had been done with good ideas being generated. It was also noted that these work plans were owned by the participants. Further that the information would be collected and put together to aid in fundraising and other form of support.

It was noted that participants could undertake any aspect of the work plan and jointly or individually fundraise to move forward the work. Thus the work plan would act as an efficient tool to further implement the *Strategy*.

- (c) The meeting had hoped to ensure participants gave input on three documents – Judicial Handbook, TB in Prisons and Declaration of Rights and Responsibilities – which was done. The authors of the documents voiced their appreciation for the feedback given and committed to incorporate and share with participants the way forward.

- (d) In relation to launching of documents, it was reported that Justice Cameron had accepted to provide the foreword to the Judicial Handbook.

- (e) Participants at the meeting deliberated and agreed to adopt a communiqué demanding more of the political declaration from the United Nations High-Level Meeting on Tuberculosis. This can be accessed here: [A communiqué issued from delegates convened under the umbrella of the Nairobi Strategy on Tuberculosis and Human Rights](#)

CLOSING REMARKS, WRAP UP AND VOTE OF THANKS

Abdulai Sessai (Sierra Leone)

In his closing remarks, Abdulai Sessai emphasized the following three core issues:

- The need to continue building partnerships in order to realize gains in TB and human rights;
- The need for good political commitments on TB;
- Empowerment and advocacy by communities to ensure governments are aware of the challenges faced by communities affected by TB;
- The need for more investment on TB.

Abdulai decried the lack of discussions on resources for different components, including communities, among others. He noted that resources were needed to ensure everybody was included in the TB response.

Dr Jennifer Furin

In her closing remarks, Dr Jennifer Furin requested participants to ‘always tell the truth’ about TB no matter where they were. Dr Furin decried how TB was based on a flawed system characterized by dishonesty. For example, she noted that reports would want the world to ignore the fact that 2 million people die of TB every day, deaths which were preventable.

Dr Furin debunked another lie noting that the global approach to TB had been a spectacular failure yet reports would indicate we had come a long way. Dr Furin called for an urgent need to tell the truth without sugarcoating – especially on the human rights that were constantly being violated; that TB is a leading killer yet there is a cure; and that the treatment itself is devastating.



When someone is bacteriologically cleared of TB but rendered incapacitated by hearing loss/can't leave their house without oxygen supply, that's not treatment success.. We need civil society to hold us accountable as we provide TB treatment; we have a cure in place~Jennifer Furin



Dr Furin further remarked that a treatment that renders somebody deaf should not be classified as ‘treatment success.’ And that there was need to hold those responsible to account.

Dr Furin concluded by urging participants to take advantage of global processes, for example, the TB meeting at The Hague later in the year ‘to air all the dirty laundry’ as pertains to TB and human rights.

ANNEXTURES

AGENDA

DAY ONE (9 August 2018)	
Time	Activity
8:15 am – 9:00 am	REGISTRATION
9:00 am – 9:20 am	WELCOME AND INTRODUCTIONS: Allan Maleche, <i>Executive Director, KELIN (Kenya)</i>
9:20 am – 9:30 am	OPENING REMARKS: Viorel Soltan, <i>Team Leader, Country and Community Support for Impact (Switzerland)</i>
9:30 am – 9:50 am	KEYNOTE ADDRESS: Justice Mumbi Ngugi, <i>High Court of Kenya (Kenya)</i>
9:50 am – 10:10 am	DISTINGUISHED REMARKS FROM THE COMMUNITY: Dean Lewis, <i>Global Coalition of TB Activists, Touched by TB, International Network of People who Use Drugs & TB People (India)</i>
10:10 am - 10:40 am	TEA/COFFEE BREAK & GROUP PHOTO
10:40 am – 11:40 am	SESSION ONE: Progress Implementing the Nairobi TB Strategy (2016 – 2018)
	<p>Chair: Lynette Mabote, <i>Regional Advocacy Team Leader, ARASA, (SouthAfrica)</i></p> <ul style="list-style-type: none"> • Brian Citro, <i>Clinical Professor of Law, Northwestern Pritzker School of Law (USA)</i> • Vivek Divan, <i>Independent Consultant, (India)</i> <p>Discussion (30 minutes)</p>
11:40 am – 12:40 pm	SESSION TWO: Documents for Input and Feedback
	<p>Chair: Allan Maleche, <i>Executive Director, KELIN (Kenya)</i></p> <ul style="list-style-type: none"> • Declaration on the Rights and Responsibilities of People with TB (revised Patients’ Charter for Tuberculosis Care)—Timur Abdullaev, <i>TB People (Uzbekistan)</i> • Judicial Handbook on TB, Human Rights and the Law – Brian Citro, <i>Clinical Professor of Law, Northwestern Pritzker School of Law (USA)</i> • TB in Prisons: An introduction to the law—John Stephens, <i>The O’Neil Institute (USA)</i> <p>Discussion (30 minutes)</p>
12:40 pm – 1:40 pm	LUNCH

DAY ONE (9 August 2018)	
1:40 pm – 3:00 pm	SESSION THREE: Group Work: Feedback on draft documents and presentation of group recommendations
	<p>Chair: Allan Maleche, <i>Executive Director, KELIN (Kenya)</i></p> <ul style="list-style-type: none"> • Declaration on the Rights and Responsibilities of People with TB (revised Patients’ Charter for Tuberculosis Care)—Timur Abdullaev, <i>TB People (Uzbekistan)</i> • Group B: Judicial Handbook on TB, Human Rights and the Law—Brian Citro, <i>Clinical Professor of Law, Northwestern Pritzker School of Law (USA)</i> • Group C: TB in Prisons: An introduction to the law—John Stephens, <i>The O’Neil Institute (USA)</i>
3:00 pm - 3:20 pm	TEA/COFFEE BREAK
3:20 pm - 4:20 pm	SESSION FOUR: Testing and Treatment Justice: Access to new drugs and diagnostics for all
	<p>Chair: Tendai Mafuma, <i>Researcher, SECTION27 (South Africa)</i></p> <ul style="list-style-type: none"> • Video; “Two Countries, Two Choices” – AIDS Free World • Dr. Jennifer Furin, <i>Lecturer on Global Health and Social Medicine, Harvard Medical School and DR-TB Training Network, USAID (USA)</i> <p>Discussion (20min)</p>
4:20 – 4:30	CLOSING REFLECTIONS
	Chair: Blessina Kumar, <i>CEO, Global Coalition of TB Activists (India)</i>
END OF DAY ONE	

DAY TWO (10 August 2018)	
Time	Activity
9:00 am – 9:20 am	INTRODUCTION & FRAMING THE CONVERSATION: Brian Citro, <i>Clinical Professor of Law Northwestern Pritzker School of Law (USA)</i>
9:20 am – 9:30 am	KEYNOTE ADDRESS: Justice Edwin Cameron, <i>Constitutional Court of South Africa (South Africa)</i>
9:30 am – 9:40 am	DISTINGUISHED REMARKS FROM THE COMMUNITY: Timpiyan Leseni, <i>Founder Talaku, (Kenya)</i>
9:40 am – 11:00 am	SESSION FIVE: Talk Show: What’s happening in TB & human rights? A discussion with people on the frontline.

DAY TWO (10 August 2018)

	<p>Chair: Alberto Colorado, <i>International Public Health Consultant, (USA)</i></p> <ul style="list-style-type: none"> • Priyam Lizmary Cherian, <i>Legal Officer, Lawyers Collective (India)</i> • Gisa Dang, <i>Consultant, Treatment Action Group (USA)</i> • Dr. Eunice Mailu, <i>National TB Programme, (Kenya)</i> • Lynette Mabote, <i>Regional Advocacy Team Leader, ARASA (South Africa)</i> • James Malar, <i>Community, Rights and Gender Advisor, Stop TB Partnership (Geneva)</i> <p>Discussion (25 minutes)</p>
11:00 am – 11:20 am	TEA/COFFEE BREAK
11:20 am – 12:20 pm	<p>SESSION SIX: Roundtable: What next for the draft Political Declaration for the UN High-Level Meeting on TB?</p> <p>Chair: Elvi Siahaan <i>Country Director of Yayasan MAP Internasional (Indonesia)</i></p> <ul style="list-style-type: none"> • Dean Lewis, <i>Global Coalition of TB Activists, Touched by TB, International Network of People who Uses Drugs & TB People (India)</i> • John Stephens, <i>The O’Neil Institute (USA)</i> • Austin Obifuna, <i>Executive Director, Afro Global Alliance (Ghana)</i> <p>Discussion (20min)</p>
12:20 – 1:10pm	<p>SESSION SEVEN: Group Work Prioritization of activities under the Nairobi TB Strategy</p> <p>Chairs: John Stephens, <i>The O’Neil Institute (USA)</i> & Tendai Mafuma, <i>Researcher, SECTION27 (South Africa)</i></p>
1:10 am – 2:20 pm	LUNCH
2:20 pm – 3:00 pm	<p>PLANNING THE NEXT STEPS: Strategy Session to Advance a Human Rights Based-Approach to TB</p> <p>Chairs: Brian Citro, <i>Clinical Professor of Law, Northwestern Pritzker School of Law (USA)</i> and Allan Maleche, <i>Executive Director, KELIN (Kenya)</i></p>
3:00 – 3:20pm	<p>CLOSING REMARKS, WRAP UP & VOTE OF THANKS</p> <p>Chairs: Dr. Jennifer Furin, <i>Lecturer on Global Health and Social Medicine, Harvard Medical School and DR-TB Training Network, USAID (USA)</i> & Abdulai Sessai (Sierra Leone)</p>

CONCEPT NOTE

Objectives:

1. **Measure progress** made in implementing the Nairobi Strategy on TB and Human Rights;
2. **Develop and finalize a workplan**, and mobilize human and financial resources, to guide the next two years of implementation of the Nairobi Strategy on TB and Human Rights;
3. **Review the draft Patients' Charter for Tuberculosis Care and launch the new Judicial Handbook** on TB, Human Rights and the Law; and
4. **Draft a communique** on the importance of the Nairobi Strategy on TB and Human Rights for submission to the UN HLM on TB to be shared to the Co-Chairs

Background:

Tuberculosis (TB) remains a critical global health challenge. It ranks as the leading cause of death from an infectious disease, killing more people each year than HIV/AIDS. An estimated 1.8 million people died and 10.4 million people fell ill with TB in 2016. Nearly 80% of the global burden of TB is found in 22 countries, nine countries in Sub-Saharan Africa belong to the 22 high burden countries, and India alone accounts for 27% of the global disease burden.

A human rights-based approach to TB articulates and upholds the rights of people affected by TB, including the rights to life, health, nondiscrimination, privacy, informed consent, housing, food and water. The approach focuses on the social and economic determinants of the disease, addressing stigma, discrimination and environmental conditions. It articulates the domestic and international legal obligations of governments and non-state actors to ensure good quality testing and treatment for TB is available and accessible without discrimination. The approach also aims to create an enabling legal environment for the research and development of new, more effective TB drugs and diagnostics, and to lower the prices of existing drugs, including new medicines for MDR-TB, and advanced diagnostics.

Against this backdrop, on 24 and 25 June 2016, the Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN), Stop TB Partnership, University of Chicago Law School, and the Judicial Training Institute of Kenya partnered to conduct the Judicial Dialogue on TB, Human Rights and the Law. The Judicial Dialogue was attended by prominent judges and magistrates from the region, TB survivors, anthropologists, and legal, medical and public health experts from across the world. The Judicial Dialogue sensitized judges on the relationship between TB, human rights and the law, and provided them an opportunity to engage directly with people affected by TB.

This Judicial Dialogue also led to the development of a global action plan to promote a human rights-based approach to TB: The **Nairobi Strategy on TB and Human Rights**. The key components of the Nairobi Strategy include:

- (a) **Empowerment and support of networks of people with TB**, TB survivors and broader civil society at global, regional and national levels;
- (b) Enhancement of judiciary and legal communities' awareness and understanding of a human rights-based approach to TB; and
- (c) Expansion of legislators' and policymakers' capacity to incorporate human rights- based approaches to TB into laws and policies.

Justification:

It is now almost two years since the development and launch of the Nairobi Strategy on TB and Human Rights. During this time, implementation of this global action plan, with minimal funding, has resulted in tremendous gains in the field of TB and human rights. Notable achievements include:

- i. The TB, Human Rights and the Law Case Compendium, with summaries of legal cases involving TB from more than 20 countries, researched in six languages, was published and disseminated widely;
- ii. TB Legal Environment Assessments, founded on and in promotion of human rights principles, have been conducted and are ongoing in several countries, including Kenya and Nigeria;
- iii. The Judicial Handbook on TB, Human Rights and the Law has been developed and drafted through an inclusive, ongoing process;
- iv. Lawyers, law enforcement officers and health care workers have been trained on TB and human rights at national and regional levels;
- v. Initiatives to develop, empower and support networks of people with TB, TB survivors and broader civil society at global, regional and national levels, have been launched; and
- vi. Scholarship and research on TB, human rights and the law has been conducted and published in books and journals.

It is against this backdrop that we propose a high-level stakeholder workshop to: measure progress made in implementing the Nairobi Strategy on TB and Human Rights; to plan and mobilize resources for the next two years of work; and to launch the revised Patients' Charter for Tuberculosis Care and the new Judicial Handbook on TB, Human Rights and the Law. This workshop will provide a critical point of reflection on the past two years and a strategic moment for planning and investment in the next two. Noting that the first ever High Level Meeting on TB will take place in September, this workshop will allow for the participants to draft and finalise a statement on the importance of using a rights based approach to address TB issue. This statement will be submitted to the co-chairs of the high level meeting.

Work and Activities:

1. Survey and document progress made in implementing the Nairobi Strategy on TB and Human Rights, conducted by an Independent Consultant;
2. Develop a draft costed workplan, with human and financial resource commitments, to guide the next two years of implementation of the Nairobi Strategy on TB and Human Rights to be adopted at the meeting;
3. Design, print and publish of the Judicial Handbook on TB, Human Rights and the Law;
3. Discuss and provide feedback to the revised Patients' Charter for Tuberculosis Care;
4. Organize and conduct high-level stakeholder meeting; and
5. Draft a communique for submission to the Co-Chairs of the High Level Meeting on TB

Expected Outcomes:

1. Sensitization of high-level stakeholders on promotion of a human rights-based approach to TB through implementation of the Nairobi Strategy on TB and Human Rights;
2. Finalized, costed workplan, with human and financial resource commitments, to guide the next two years of implementation of the Nairobi Strategy on TB and Human Rights;
3. Feedback provided to revised Patients' Charter for Tuberculosis Care; and
4. Publication of Judicial Handbook on TB, Human Rights and the Law.
5. Submission of a draft communique on TB and rights to the Co-Chairs of the High- Level Panel Meeting

Principal Organizers and Facilitators:

Stop TB Partnership, Community, Rights and Gender Division

Allan Maleche, *Executive Director, KELIN*; Board Member Developing Country NGO Constituency of the Global Fund Board

Brian Citro, *Assistant Clinical Professor of Law, Northwestern Pritzker School of Law*; *Technical Assistance Consultant, Stop TB Partnership*

Timur Abdulaev, *Community Representative, Stop TB Partnership*; *Board Member, TBPeople*; *Steering Committee Member, TB Europe Coalition*

LIST OF PARTICIPANTS

NAME	COUNTRY	ORGANIZATION
Abdulai Sessai	Sierra Leone	Civil Society Movement Against Tuberculosis – Sierra Leone
Allan Maleche	Kenya	KELIN
Austin Obiefuma	Ghana	Afro Global Alliance
Blessina Kumar	India	Global Coalition of TB Activists
Cherian Priyam	India	Lawyers Collective
Choub Sok Chamreun	Cambodia	KHANA
Colorado Alberto	USA	International Public Health Consultant
Dang Gisa	Germany	Treatment Action Group
Dean Lewis	India	Global Coalition of TB Activists, Touched by TB, International Network of People who Use Drugs & TB People (India)
Divan Vivek	India	Independent Consultant
Brian Citro	USA	Northwestern Pritzker School of Law (USA)
Dr Jennifer Furin	USA	Harvard Medical School and DR-TB Training Network
Dr Stellah Bosire	Kenya	Kenya Medical Association
Elvi Siahaan	Indonesia	Yayasan MAP Internasional
Eunice Mailu	Kenya	National TB Programme (NTLD)
Evaline Kibuchi	Kenya	Stop TB Partnership (Kenya)
Everlyne Timpiyian	Kenya	Talaku TB Community Organisation
James Malar	Switzerland	Stop TB Partnership (Geneva)
John Stephens	South Africa	O'Neill Institute
Justice Mumbi	Kenya	Judiciary (Kenya)
Lynette Mabote	South Africa	ARASA
Mafuma Tendai	South Africa	Section 27
Mugo Wariara	Kenya	MSF
Stephen Anguva	Kenya	Pamoja TB Group
Thorn Paul	United Kingdom	TB People
Timur Abdullaev	Uzbekistan	TB People
Vioel Soltan	Switzerland	Stop TB
Wafula Timothy	Kenya	Rapporteur
William Dekker	Kenya	Impact Africa
Lucy Ghati	Kenya	KELIN
Margaret Wambui	Kenya	KELIN
Katherine Karambu	Kenya	KELIN

Nairobi Office
4th floor Somak House Mombasa Road

✉ 112 - 00202 Nairobi
☎ +254 788 220 300
☎ +254 708 389 870
✉ info@kelinkenya.org
🌐 www.kelinkenya.org
🐦 @KELIKenya

Kisumu Office
Aga Khan Road Opp Jalaram Academy

✉ 17708 - 40100 Kisumu,
☎ +254 (57) 253 2664
☎ +254 708 342 197
✉ info@kelinkenya.org
🌐 www.kelinkenya.org
📘 Facebook/kelinkenya