

Report

First Meeting of the Stop TB Partnership Task Force on TB and Human Rights Berlin, 9th-10th November 2010

Summary:

The first meeting of the Stop TB Partnership Task Force on TB and Human Rights, convened by WHO and UNAIDS, was held in Berlin on 9th-10th November 2010, prior to the 41st Union World Conference on Lung Health, and was attended by 18 participants. The terms of reference of the Task Force were agreed, key issues and challenges moving forward were identified and discussed, case studies and issues briefs were reviewed, an outline structure of the proposed policy framework was agreed upon, and suggested priorities for an action plan were proposed for the coming year, incorporating key events and opportunities ahead.

The agenda and list of participants are included as **Annexes 1 and 2**.

Background:

- In mid-2008, the WHO Strategic and Technical Advisory Group for Tuberculosis (STAG-TB) recommended that WHO pursue a human rights-based approach to TB prevention, diagnosis, care and support, and the WHO Stop TB Strategy now includes among its objectives - to protect and promote human rights in TB prevention, care and control.
- Among the recommendations of the Stop TB Partners' Forum in Rio de Janeiro in March 2009 was the creation of a Task Force on TB and Human Rights, and this notion was supported by the UNAIDS Human Rights Reference Group in July 2009.
- The establishment of the Task Force and draft objectives were approved by the 18th Stop TB Partnership Coordinating Board in Hanoi, Vietnam, on May 2010, based on a proposal made WHO and UNAIDS, which jointly offered to provide the Secretariat.
- A planning committee of WHO and UNAIDS focal points with representatives of the Open Society Institute (OSI) and Human Rights Watch formed a planning committee. WHO, UNAIDS, the Stop TB Partnership Secretariat and OSI provided initial financing for the work of the Task Force. An early consultation on membership and aims of the Task Force was held in Cancun, during the Union Lung Health Conference in December 2009.
- WHO Stop TB Department and the WHO STAG-TB, UNAIDS and the Stop TB Partnership Secretariat have given green light to drafting of a policy framework that can be considered by all three organizations for publication as a joint document, with endorsements as well from other partners.
- A working draft briefing note on TB and Human Rights was drafted, and a webpage created on the Stop TB Partnership website, <http://www.stoptb.org/global/hrtf/>
- The Secretariat and planning group defined a process for selecting members for the Task Force, and it was approved by the Stop TB Partnership Executive Secretary. Key constituencies were identified and representatives from each constituency were invited to nominate candidates for Task Force membership to

represent and canvas the opinions of their respective constituencies. The following constituencies were identified:

- Health and human rights experts
- Health and human rights advocates
- Patient advocates (including MDR-TB patients)
- National TB Programme managers
- Migrant population advocates
- People who use drugs and alcohol
- Prisoners advocates
- Health workers
- Community Task Force (CTF) of the Stop TB Partnership
- TB and Poverty Subgroup of the Stop TB Partnership
- WHO Task Force on Addressing Ethical Issues in TB Care and Control Programmes (“Ethics Task Force”)
- Ethics Task Force
- Steering Group of the Global Indigenous Stop TB Initiative
- Access to new tools advocates/public-private partnerships for new TB tools development

In addition to constituency members, the Task Force includes representatives of UN agencies and other institutional members:

- UNAIDS (Co-Secretariat for the Task Force)
- WHO (Co-Secretariat for the Task Force)
- UNDP
- UN Office of the High Commissioner for Human Rights (UNOHCHR)
- International Organization for Migration (IOM)
- Open Society Institute (with Secretariat, core planning team for the Task Force)
- Human Rights Watch (with Secretariat, core planning team for the Task Force)
- Global Fund to fight AIDS, Tuberculosis and Malaria

First Task Force Meeting Objectives

1. To review and endorse the terms of reference, membership of the Task Force and briefing note
2. To review relevant issues in the current health and human rights agenda
3. To review existing guidance documents and agree on the outline and major content of the policy framework
4. To review supporting case studies and issues briefs
5. To map out an action framework for the coming year, with key events and partners
6. To identify priority next steps for policy development and implementation

1. Review of terms of reference, membership of the Task Force and briefing note

a) Terms of Reference

The Task Force reviewed the draft TOR, revised and adopted them as follows:

The aim of the task force is to advance the protection and promotion of human rights in pursuit of universal access to TB prevention, diagnosis, treatment, care and support so as to advance health, development and an effective response to TB,

including for the most at risk and vulnerable, through the implementation of rights-enhancing policies, strategies and programming.

The purpose of the task force will be to develop and promote a Stop TB policy framework and strategic agenda, embedded within the fifth objective of the Stop TB Strategy¹ and within the Global Plan to Stop TB, that will be taken up and implemented by a wide range of stakeholders within and beyond the TB community.

Task Force Objectives:

1. Develop an evidence-based policy framework for a rights-based approach to TB prevention, diagnosis, treatment care and support
2. Develop and implement a strategic agenda and first year plan to pursue a rights-based approach through a wide range of stakeholders
3. Mainstream human rights based approach in Stop TB Strategy, Global Plan and Stop TB Partnership and Working Group efforts
4. Advocate for adoption and implementation by other constituencies beyond TB
5. Mobilize (human, financial and political) resources
6. Monitor and evaluate first actions

b) Membership

Suggestions were made by some members to increase country, geographic and language representation as well as increasing representation of certain groups such as migrants and MDR TB patients. Participants agreed, however, that as a time-bound entity, the Task Force needs to remain agile and manageable in size to fulfil its immediate and pressing objectives and that, whilst other constituencies might be added, increasing the Task Force size might limit its efficiency. The Task Force members' role, as accepted, will be to reach out to their respective networks for input, dissemination and feedback on the Task Force activities. Special effort will be needed to consult more broadly (especially across languages and regions) on all draft Task Force products.

It was also noted that accountability and representation from TB patient and civil society groups need strengthening, and it was recommended that, as part of a rights-based approach, it will be important for the Task Force to consider both how it can foster the development and unity of the weaker voices and constituencies and how it can ensure broader participation by those communities in the delivery of the specific Task Force objectives, in collaboration with other partners. Lessons can be learned from the building of HIV/TB civil society engagement and solidarity.

c) Briefing Note

The draft briefing note on TB and Human Rights was reviewed, and further additions were recommended under the human rights concerns section. Note: subsequent to the meeting these changes were made and formatting of document improved. **The revised briefing note is attached.**

¹ The Stop TB Strategy's objectives are (see also for further reference http://www.who.int/tb/strategy/stop_tb_strategy/en/index.html) :

- Achieve universal access to high-quality care for all people with TB
- Reduce the human suffering and socioeconomic burden associated with TB
- Protect vulnerable populations from TB, TB/HIV and multidrug-resistant TB
- Support development of new tools and enable their timely and effective use
- Protect and promote human rights in TB prevention, care and control

Action Points:

1. TF members to actively extend to their constituency networks and canvas opinions from network members on all TF outputs.
2. Secretariat to develop a mailing list for broad consultation on draft TF documents and TF members will provide names for this mailing list.
3. Finalised TB and human rights briefing note to be distributed widely including to programme managers, WHO and UNAIDS Country Offices, and via Global Fund to CCM members and on the relevant list-serves and social media platforms.
4. Translation and dissemination of draft materials for Russian speaking countries was offered by Timur Abdullaev.

2. TB and the Health and Human Rights Agenda**a) Priorities and lessons learnt from HIV/AIDS experience**

Jason Sigurson provided an overview on the history and current priorities of the HIV and human rights agenda of UNAIDS, including its guidance, tools, and products. He reviewed declarations, guidance reports, monitoring of national actions based on the measures defined in the guidance, and efforts to reinforce rights-based language, human rights obligations, and examination of legal and social environments. He noted important attention now is needed on legislative reform, law enforcement, and access to justice. He referred to recently developed guidance based on evidence that HIV stigma can be reduced, and the group discussed how the Stigma Index might be examined for further modification for use in TB. He reinforced the benefits of focusing on overcoming the worst legal and social blocks. The TF members reaffirmed the great value in collaborating and learning from UNAIDS, their reference group, from partnerships with civil society and from the range of HIV experiences at national level. Note was also taken of the opportunity to build relationships with other partners such as the Global Fund - such as through practical guidance to applicants on a rights-based approach to TB projects/programmes - as has been successful for UNAIDS collaboration with the Fund, and for advancing other TB priorities (eg WHO and Stop TB Partnership work with the Fund on applicant guidance).

b) Related public health law initiatives: Larry Gostin reported on his collaborative work with the WHO Health and Human Rights team, together with the International Development Law Organization (IDLO) on the development of a public health law manual. The manual focuses on the needs of low and middle income countries and on the reform of domestic public health laws. It will include content on infectious diseases and related concerns around legal obligations and duties as well as the Siracusa Principles etc. It was proposed that the Task Force could serve as one peer review group for the product. According to the WHO team, a draft should be able to be circulated in late Spring, 2011, and TF feedback would be highly welcomed.

The O'Neill Institute is also involved in several other related projects that may be of interest to the Task Force. These include development of a health and human rights database that may be of interest (including results of litigation). Another initiative is the Joint Action and Learning Initiative (JALI) and he will share more information on this and on the related notions of a "Global Health Compact" addressing services, obligations on right to health at country level, obligations of the international community, and ideas on global health governance structure.

c) Involuntary detention

Immediate concern was raised about the recent involuntary detention of TB patients in Kenya, including detention in a criminal facility, and resulting from application of long-unused public health legislation in Kenya. This had resulted in a major outcry within and beyond the country, and eventual release of the patients. We are aware that several European and Southern African countries in the last two years had been considering reinforcing or applying new legislation to enable detention of patients. The Task Force Members noted that these cases highlighted that many country authorities appeared to lack awareness of the Siracusa Principles, and recent WHO advice, on the very rare circumstances where involuntary detention was warranted and the major responsibilities of Government to act to reduce and prevent the conditions under which patients may choose to refuse treatment or require involuntary detention or isolation. Furthermore there was concern that the due process measures required under most laws, and reflected in the Siracusa Principles may not be in these cases properly observed.

The participants noted that these instances suggested that WHO and Stop TB and human rights partners should act to reinforce awareness of policy recommendations and relevant human rights principles. OSI also noted that it aimed to support Kenyan NGOs to hold a consultation in 2011 to review the cases there and to draw lessons learned. Based on this experience the Task Force may wish to consider further recommendations for further regional and/or global consultation on the lessons learned. (Note: subsequent to the meeting OSI has provided support to the Secretariat to contract a review of Southern African public health legislation relative to TB prevention, treatment and care.)

d) Participants raised the importance of promoting more appropriate **human rights based language by the TB community** that promotes equal partnership with persons and communities who are vulnerable, at risk or affected by TB (including patients in treatment); not only holding them responsible as rights holders but also empowering and including them as duty bearers and drivers of policy design and implementation. Language, such as 'TB control', 'intervention', 'defaulter', and 'suspect', does not encourage empowerment or support of people living with TB and is not aligned to a human rights approach.

e) Juana Sotomayor (UNOHCHR - **Office for the High Commissioner for Human Rights**) presented on the existing human rights treaty body monitoring mechanisms, special procedure mandate holders as well as other relevant actors such as national human rights institutions and economic and cultural rights networks. There is a major opportunity here to further brief these counterparts and bodies on tuberculosis and human rights issues, in order for them to further advocate for action on specific concerns. Some of these key human rights mechanisms are:

- Special rapporteurs on the various different thematic mandates such as health, housing, food, water and sanitation conduct two reporting missions a year.
- The Committee on the Elimination of Discrimination against Women (CEDAW)
- The Committee against Torture (CAT) and the subcommittee for the prevention of torture (SPT)
- The Committee on Migrant Workers (CMW)

Also the High Commissioner is independent of the committees and special rapporteurs and could serve as a powerful advocate. Additionally, OHCHR has approximately 60 field presences (national and regional offices as well as human rights advisors to UN country teams and human rights components of peace

missions) which can serve to disseminate information and to advocate for the protection of HR of persons with TB.

There are many opportunities for awareness-raising of TB also in relation to health-related discrimination, and in light of positive and negative obligations of states (what states should and should not do), on raising TB within the context of General Comment 20 (Economic, Social and Cultural Rights). Another potential area of work could be defining human rights indicators related to TB based on experiences in other fields. The Secretariat is ready to help to open doors to meet more colleagues at OHCHR. The next TF meeting in Geneva offers one opportunity. TF members voiced their support, especially for efforts that bridge with other health priorities, that bring help and monitoring possibilities at country level, that can help further legal reform, and continuity of care for vulnerable populations. From HIV, lessons have been learnt on how to get new human rights partners to speak on HIV issues.

f) Patients' Charter: Case Gordon invited colleagues , Celina Menezes and Maxime Lunga, to present on the Patients' Charter for TB Care as a key document in advancing a rights-based approach at country and local level. The group discussed the need to help support and promote further use of the Patients' Charter and its endorsement by additional partners.

Action Points:

1. Secretariat will seek out further information on the HIV stigma index and seek TF guidance and engagement on how it might be adapted for TB. TF to consider submitting update to the UNAIDS Human Rights Reference Group for their March Meeting (J. Amon sits on the Reference Group) - see also <http://www.unaids.org/en/PolicyAndPractice/HumanRights/20070601> reference group
2. Task Force Secretariat to propose to Global Fund to collaborate to develop a guidance note on how to incorporate TB human rights concerns in Global Fund applications.
3. Task Force recommends that WHO and the Stop TB Partnership aim to transform/reform "standard" language used in global efforts to prevent, diagnose, and treat TB -- to ensure that it reinforces a human rights based approach and to remove words that are stigmatizing.
4. WHO to promote on its TB website again the WHO note advising that involuntary detention is very rarely appropriate and the principles that apply to its use, if ever applied, in light of the recent imprisonment of Kenyan TB patients. (eg, possibly with the launch the TB and Ethics Guidance document).
5. WHO/IDLO Draft Public Health Manual to be circulated to Task Force members for comment, as soon as draft is ready (Spring, 2011).
6. TF secretariat, working with the OHCHR, to seek out a plan for reaching out to UN human rights bodies, subcommittees and rapporteurs; and work with TF to prepare relevant briefs. The TF could consider inviting the Special Rapporteur for Health and Human Rights to the next meeting, if resources allow.
7. Task Force Members and Secretariat to encourage further endorsement and use of the Patients' Charter for TB Care, including formally by the Stop TB Partnership Coordinating Board.

3. Review of existing guidance documents and discussion on outline of policy framework

After reviewing the background materials and guidance materials from WHO, UNAIDS and other sources that can inform the preparation of the policy framework, the participants broke into two groups and prepared comments on the draft outline of the policy framework prepared by the Secretariat. The notes of those two groups' discussions are included in **Annex 3**.

Based on these notes and recommendations, the Secretariat revised policy framework outline. The revised outline is included as **Annex 4**. Changes in the outline reflect additions of themes to be addressed, and most importantly a further elaboration of the structure of the proposed framework to create a coherent framework. The framework needs to address: (a) prevention of vulnerability to tuberculosis, associated with socio-economic and behavioural determinants, through rights-protecting and enhancing actions, and (b) ensuring access to quality services for particular vulnerable groups, including overcoming stigma and discrimination that inhibits rights and ensuring research and special attention to improving rapid action to new tools and technologies.

It was also agreed that the roles and responsibilities of specific stakeholder audiences needs to be provided for each section, and groups were defined and are laid out in the revised outline.

Action Points:

1. Secretariat to revise outline policy framework based on group discussions (as noted, revised outline is attached as **Annex 4** and will need careful review and feedback from TF members).
2. Secretariat to create web workspace (including reference documents, TF materials, mailing lists, etc. for Task Force Member use) (planned for March, 2011).

4. Review of supporting case studies and issues briefs

A draft case study on ethics and human rights concerns in Moldova, financed by OSI, and issues briefs on prisons and people who use drugs were presented by Annabel Baddeley. Further editing and finalization of the case study would be pursued by the Secretariat, welcoming further comments from TF members. The Moldova case study also features highlights the ethical challenges faced in TB control and will be used by the WHO and its Task Force on Ethical Issues in TB Care and Control. WHO Task Force on Addressing Ethical Issues in TB Care and Control Programmes ("Ethics Task Force") aims to identify key ethical dilemmas to suggest solutions and to advise WHO on a range of ethical issues relating to the response to TB. WHO has finalized an ethics guidance document which covers many important dilemmas that face healthcare professionals and policy makers. The work of the Ethics and Human Rights Task Forces will be closely aligned. Ernesto Jaramillo presented on the aims and content of the ethics guidance and the document was provided to participants.

OSI has provided further financing for human rights case studies and it was proposed that the Task Force would play a key role in determining topics for case studies and means for pursuing contracts for the work to be pursued. The Task Force would also help ensure wide use of resulting case studies. This process will be pursued before the next Task Force meeting, and the TF will also further consider whether case studies should be embedded in the policy framework or serve as an accompanying document.

Joe Amon presented on an OSI study on TB, HIV and other health challenges in Zambian prisons as well as on the impact of the study on changes in prison policies. Both the Moldova case study and the OSI study reinforced the advanced evidence that exists on the rights challenges facing detainees and prisoners, and on needs and approaches/best practices to overcome such challenges. It was agreed that this will need to be one of areas for detailed guidance in the policy framework and in advocacy work of the Task Force.

Action points:

1. Secretariat to accept any further comments on Moldova case study and will finalize for use by ethics and human rights teams and partners.
2. Secretariat to develop proposed criteria for selection of case studies and seek Task Force involvement in selection of themes and approaches to pursuing the case studies, and promoting their dissemination and use.

5. Identify priority next steps and key events in action framework and stakeholders for policy development and implementation

Participants brainstormed on priority activities in addition to preparation of the policy framework that might be pursued by the Task Force in 2011. The list is still a long one and will need to be refined through email communications and planning by Task Force members. The group also noted relevant events in 2011 that might offer opportunities for advocacy, information-gathering and networking for the Task Force. See **Annex 5**.

Selection of Task Force Chair

Task Force members were invited to submit nominees among the Members to serve as Chair of the Task Force, and act in that role from the next meeting. All Task Force Members participated in the voting based on the list of nominees. WHO and UNAIDS representatives (the Secretariat) did not participate in the voting. Agnieszka Wlodarski (representative of the health and human rights advocates constituency) was elected chair and will lead the next Task Force meeting and work with the Secretariat in planning the meeting and liaising with all TF Members and partners.

Action point:

1. Secretariat to draft TOR for the Chair to be shared at the next Task Force's meeting

Dates for the next meeting

It was agreed that the next meeting should be held in the spring, after the Secretariat had time to work and communicate virtually with the Task Force in preparing a full draft of the policy framework, and had proceeded with at least some of the case studies and review work. It was recommended to hold the meeting in Geneva at the headquarters building for WHO Stop TB Department, the Stop TB Partnership Secretariat and UNAIDS. It was also suggested that this might offer an opportune moment for an open seminar on TB and Human Rights at WHO, and side discussion with other UN offices such as the UN Office of the High Commissioner for Human Rights.

Subsequent to the meeting, dates were selected based on Task Force Member availability and venue availability: **5-6 May, 2010**

Acknowledgements

Administrative and secretarial support: Jasmine Solangon

Co-chairs of the meeting: Alasdair Reid and Diana Weil

Presenters and speakers: Jason Sigurdson, Larry Gostin, Juana Sotomayor, Case Gordon, Ernesto Jaramillo, Annabel Baddeley, Joe Amon, Diana Weil and Alasdair Reid.

Rapporteur: Annabel Baddeley and Secretariat.

Annex 1

AGENDA

Stop TB Partnership

TB and Human Rights Task Force

To Advance a Rights-Based Approach to TB Prevention, Care and Control

1st Meeting
9-10th November 2010
Crowne Plaza Berlin City Centre
Nürnberger Strasse 65
10787 Berlin

Organized by WHO Stop TB Department and UNAIDS

Chairs: Alasdair Reid and Diana Weil

Tuesday 9th November 2010		
08:30-09:00	Registration	
09:00-09:30	Welcome, introductions and expectations	Diana Weil/Alasdair Reid/Giuliano Gargioni
Objective 1 : To review, finalize & endorse the terms of reference & membership of the Task Force		
09:30-09:50	Presentation of the terms of reference and membership of the Task Force	Alasdair Reid
09:50-10:15	Discussion and adoption of the TOR and membership	
10:00-10:15	Briefing note on TB and Human Rights and other reference materials	Diana Weil
10:15-10:30	General discussion	
10:30-11:00	Coffee break	
Objective 2: To review the current health and human rights agenda		
11:00-11:15	TB within the overall Health and Human Rights Agenda	D. Weil/A. Reid
11:15-11:30	HIV and Human Rights guidance and experience	Jason Sigurdson
11.30-11:45	WHO guidance on public health law and human rights	Larry Gostin
11:45-12:30	Discussant – Juana Sotomayor - Comments on UNOHCHR Moderated discussion	
12:30-13:30	Lunch (provided)	
Objective 3 : Review existing guidance documents and agree outline and content of policy framework		
13:30-13:45	The patient's charter for TB care and control - development	Case Gordon

	and use to date	(moved to day 2)
13:45-14:00	WHO Guidance on Ethics in TB prevention, care and control	Ernesto Jaramillo
14:00-14:20	Presentation of an outline of the Policy Framework	Diana Weil/Alasdair Reid/Erin Howe
14:20-16:00	Group work: to discuss draft Policy Framework, background research, subthemes and working groups (including coffee)	All
15:50-17:00	Rapporteur feedback, discussion and conclusion	All

Wednesday 10th November 2010

Objective 4: To review supporting case studies and issues briefs

09:00-09:15	Moldova: case study on ethics and human rights issues in TB prevention, care and control	Annabel Baddeley
09:30-09:45	TB, HIV and Human Rights in Zambian Prisons	Joe Amon
09:45-10:15	Discussion	
10:15-10:45	Tea/Coffee Break	
10:45-11:05	Issues Briefs – Prisons; People who use drugs and alcohol	Annabel Baddeley
11:05-12:00	General discussion on existing issues briefs and need for further issue briefs	
12:00 -13:00	Lunch (provided)	

Objective 5: To identify priority next steps and key events for policy development & implementation

13:00-13:15	Proposed action framework and key events	Diana Weil/Alasdair Reid
13:15-14:45	Group work on action framework, key events and stakeholders	All
14:45-15:00	Tea/Coffee Break	
15:00-15:45	Rapporteurs feedback and discussion	All
15:45-16:00	Conclusions, Next Steps and selection of Chair for the Task Force	Secretariat

Annex 2

List of Participants
First Meeting of
Stop TB Partnership
Task Force on TB and Human Rights
Berlin, Germany
9-10 November 2010

Task Force Members

1. Health and human rights experts	Lawrence O. Gostin Georgetown University Law Center
2. Health and human rights advocates	Agnieszka Wlodarski SECTION27 , incorporating the AIDS Law
3. Representative of the Community Task Force (CTF) of the Stop TB Partnership	Robert Nakibumba
4. Migrants advocates	Einar Heldal
5. Representative of the TB and Poverty Subgroup of the Stop TB Partnership	Gillian Mann Liverpool School of Tropical Medicine
6. Representative of the WHO Task Force on Addressing Ethical Issues in TB Care and Control	Ronald Bayer Mailman School of Public Health unable to attend
7. New tools access advocates and public-private partnerships for new TB tools development	Jennifer Woolley Aeras Global TB Vaccine Foundation
8. People Who Use Drugs and Alcohol	Raffi Balian International Network of People Who Use Drugs (INPUD)
9. Prisoner advocates	Raed Abu Rabi ICRC (unable to attend)
10. Health Workers	Julia Seyer World Medical Association World Health Professional Alliance WHPA
11. Patient Advocates	Case Gordon IMAXI Cooperative Timur Abdullaev
12. Representative of Steering Group of the Global Indigenous	Regional Chief Wilton Littlechild (unable to attend)

Stop TB Initiative	
13. NTP managers	Dr Nathan Kapata Zambian TB and Leprosy Programme

Institutional Members

1. World Health Organization (WHO)	Diana Weil
2. UNAIDS	Alasdair Reid
3. UN Development Programme (UNDP)	Mandeep Dhaliwal <i>(unable to attend)</i>
4. International Organization for Migration (IOM)	Davide Mosca
5. Open Society Institute (with Secretariat, member of core planning team for the Task Force)	Erin Howe
6. Human Rights Watch (with Secretariat, member of core planning team for the Task Force)	Joseph Amon
7. The Global Fund	Andy Seale <i>(unable to attend)</i>

Task Force Secretariat

Jasmine Solangon, STB/WHO Sara Faroni, STB/WHO <i>(unable to attend)</i>

Other Participants

1. Juana Sotomayor	UN Office of the High Commissioner for Human Rights (UN OHCHR) (later joined as institutional member)
2. Jason Sigurdson	UNAIDS
3. Ernesto Jaramillo	WHO/Stop TB
4. Masoud Dara	WHO/EURO
5. Annabel Baddeley	Consultant

Annex 3

Notes from breakout groups on policy guidance document outline

Work group 1 notes:

Audience/Who do we want to reach:

- Need dissemination plan targeted to different audiences: NTPs, civil society, human rights advocates, funders, legislators, ministries, policy makers, implementers, UN and other development agencies, people living with TB & MDR TB, people at risk of TB, employers, unions, public and private providers.
- Should consist of core principles with roles and responsibilities for each audience.

Structure and content:

- Start with why TB is a human rights imperative and why is TB & HR and issue of concern.
- Keep section with introduction and explanation of links between TB and human rights.
- Add “dignity” as a principle of human rights-based approach.
- Move relationship to ethics and public health law section to beginning
- Safety issues should be included. Freedom from violence, safe working environment, detention – infection control.
- Consider three principles (prevention, access, quality in three separate sections). Consider adding sections on care and diagnosis.
- Or basic principles – prevention, and then access to diagnosis, treatment & care. Quality linked with everything.

Underlying HR approach -- accountable representation of the people most affected. People should have the right to a voice and that voice should be held accountable. E.g. Legal counsel, ombudsmen.

- Research – separate section – protection of human subjects, operational research, etc.
- How can structure facilitate implementation?
- Palliative care should be within quality of care section.

Prevention:

- ILO/WHO work re: prioritizing access for health care workers (HCWs)
- Pairing housing improvements, living conditions improvements with TB treatment interventions with rights-based focus.
- What needs to be done in terms of housing and nutrition. Even though not entirely within realm, give concrete recommendations for policy makers.

Access:

- HIV
- Sexual/reproductive health
- Neglected tropical diseases (e.g. schisto)?

- Client-centred care
- Integrated treatment (HIV, TB, HepC, drug tx)
- Zambia –example of intensified case finding; costs
- Community based care
- Migrants and access (Russian prisons, Zim-RSA border, US-Mexico border, North Star PHC clinics on transport routes, SADC – standardizing cross-border policies, legal aid for Kazakh patients, don't deport patients on treatment.

Quality

- QA for HIV testing and counselling (linked from dx to tx)
- Community Advisory Boards/PAB - civil society as oversight mechanism.
- Underline that public health and human rights interventions are mutually beneficial.
- Accountability
- Monitoring standards.

Vulnerable groups

- Separate illicit drug users from alcohol/nicotine users because of criminalisation issues.
- Issues in ethics guidance – key to address
- Define key issues for human rights approach for TB.

Work group 2 notes:

General points that need to be considered:

Who is the audience – who do we want to reach? Might want one geared towards civil society, parliamentarians, health professionals. Need a dissemination plan geared to the different audiences.

- Policy document needs to be clear and simple to be read by civil society or a member of parliament with no human rights or TB background – a primer for TB & human rights.
- What about humanitarian crisis context/mass migration/environmental disaster? Include mention in 3, 5 and constituencies. Needs to take into account the different humanitarian contexts and to engage the humanitarian community.

Structure and content:

- Move/join III. HR, and V what is a rights-based approach, then have TB followed by rights-based approach to TB.
- Best practice/case studies make it easier to read or a companion document?
- Consider including case studies to make text more readable/as companion document.
- Central blue boxes to be replaced by “services for prevention, diagnosis, treatment, care and support”. Social determinants, availability, accessibility (including affordability), acceptability and quality (in addition to items listed, add continuity of care). The AAAQ all vital for services for prevention, diagnosis, treatment, care and support.
- Social determinants should be referred to not just “prevention services”. Should be explicit that governments should not shrug off the responsibility of health.

Information, transparency, accountability, participation to be included in rights-based approach (to be covered in section 5). Capacity building for applying a rights-based approach also to be incorporated.

- Vulnerable groups. Need for disaggregated data, epidemiological data and research. But bear in mind the Oviato Convention WHA Declaration of Helsinki – legal document for research and patient privacy.
- Create new section on research- overlaps with research innovation and rights - Right to access of scientific technology.
- A section is needed on monitoring, evaluation and related research of *implementation of these guidelines*.
- Under quality of care be explicit about the pillars in health systems strengthening needed for quality. Address privacy and confidentiality under access and quality (both areas).
- Detention as “last resort” need more guidance on what this means. Due process needed to be made explicit. Criteria of responsibilities, definitions, alternatives, reasonable course of action.

Annex 4

DRAFT OUTLINE FOR POLICY FRAMEWORK **On a Rights-based Approach to TB prevention, care and control**

I. Introduction

- a) What are human rights and why are they important for TB prevention, diagnosis, treatment and care and its eventual elimination
- b) What is TB, Stop TB Strategy and Global Plan to Stop TB
- c) Overlap/differences/complementarities between human rights and ethical principles for TB prevention and care.

II. Aim, audience and process of development of the policy framework -

To give specific, simple, cogent guidance targeted to each stakeholder group on roles and responsibilities in the formulation and implementation of a rights-based approach in TB, and have dissemination plan targeted to each audience including :

- States - policy makers and implementers including legislators/parliamentarians, ministries (e.g. Health, Justice), NTPs, courts, institutional managers and health care workers .
- Intergovernmental organizations, UN, development agencies, and global partnerships
- Non-governmental organizations (NGOs), community based organizations and civil society - including people with TB, former patients and their families
- Private sector - including private providers, pharmaceutical industry , unions and labour

III. What is a rights-based approach?

To include a description of each of the following principles underpinning a human rights-based approach to tuberculosis:

- a. Put the person and affected communities at the centre, as equal partners, driving health policy, providing the individual and groups with the tools to participate and claim specific rights
- b. Identify, inform and empower the most marginalized, at risk and vulnerable
- c. Assure dignity of patients and those affected
- d. Address socio-economic determinants and human rights implications of TB policy, legislation and programming
- e. Overcome institutional constraints and capacity gaps
- f. Support an integrated multi-sectoral response to TB
- g. Provide accountability mechanisms for governments, the international community and civil society and assure transparency
- h. Provide a platform for documenting and sharing best practices, supporting advocacy and social mobilization

V. Overlap/differences between public health law, ethics and human rights

- This section will describe the relationship between public health and human rights focusing on the responsibilities of the states to provide information and access to diagnostics, treatment, care and support, and protection from infection. It will also include an overview of liberty restricting measures / Siracusa principles and notification, reporting, follow-up (and confidentiality) measures (these issues will be further developed under para VII point c).
- Lessons learned about legal reform efforts to improve access to care for migrants; to review/modify liberty restricting measures and other key experiences will also be outlined.

VI. Rights promoting actions to prevent vulnerability to TB

This section will discuss the key socio-economic determinants and biological risk factors that increase vulnerability to TB and will also discuss related stigma and discrimination including in terms of public policy and legislation that can enhance the vulnerability.

Better disaggregated data, epidemiological data and research on vulnerable groups and vulnerabilities will also be highlighted as crucial instruments needed to identify and empower the most vulnerable.

A) Socio- economic and behavioural determinants

This section will focus on the rights-related aspects of key socio-economic and behavioral determinants that enhance the vulnerability to TB , and will define recommended actions by key stakeholders.

- Poverty (including poor nutrition, education, housing and lack of employment and social security)
 - Key issues faced by key vulnerable group such as women and children, homeless people; drug users; migrants
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Workplace
 - Key issues faced by workers (health workers)
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Migration
 - Key issues faced by migrants
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Detention/imprisonment
 - Key issues faced by prisoners
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Humanitarian crisis
 - Key issues faced by refugees and internally displaced persons
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- HIV infection
 - Key right issues faced by people living with HIV
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Drug Use
 - Key issues faced by drug users, including issues linked to criminalization of drugs and drug users
 - Rights responses (with reference to human rights instruments) and action steps for each stakeholder group
- Smoking and alcohol
 - key issues faced by smoking and alcohol users

- rights responses (with reference to human rights instruments) and action steps for each stakeholder group

VII. Rights promoting actions to increase access to quality TB diagnosis, treatment and care

This section will discuss key challenges and barriers to access (availability, accessibility, acceptability and quality) to quality TB diagnosis, treatment and care, focusing on key issues faced by affected groups. Under each challenge, specific right responses and action steps for each stakeholder group will be developed. Particular attention will be paid to interventions that promote community based care, patients centred care and capacity-building approaches as well as the development of accountability and monitoring standards. Accountable representation of the people most affected will be highlighted as a fundamental principle underpinning the HRBA.

A) Financial, geographical and systemic barriers to access to quality care

This paragraph will focus on direct and indirect costs associated with seeking TB care - especially of maintaining treatment or seeking MDR-TB treatment. Particular attention will be paid to approaches to health system strengthening and pillars needed for quality as well as to harmful or unsafe practices in the public and private sectors. The following challenges will be addressed focusing on some vulnerable groups and specific right responses and action steps for each stakeholder group.

- Financial barriers
 - Key issues faced by key vulnerable groups
 - Rights responses and action steps for each stakeholder group
- Geographical barriers (*same structure as described above*)
- Lack of quality services (*same structure as described above*) (*eg lack of personnel, integrated services or other barriers*)
- Lack of access to diagnostics and drugs (*same structure as described above*)
- Poor regulation enforcement or lack of regulation in the private sector (*same structure as described above*)

B) Stigma and Discrimination

This paragraph will focus on stigma and discrimination as a cross-cutting human right issue that can prevent access and use of quality TB prevention, diagnosis and care. Discrimination will be defined to include not only TB stigma but also overlapping inequalities, identifying groups among whom inequalities reflect a lack of health equity. Particular attention will be given to the following issues and the related rights responses and action steps for each stakeholder group:

- TB discrimination and stigma
- Gender inequality and TB
- TB and HIV
- MDR-TB

C) Liberty restricting measures

Guidance on the rare circumstances for involuntary detention (this is a subset of liberty restricting measures):

- Definition of involuntary detention, isolation and incarceration
- Defining criteria of responsibilities
- Ensuring alternatives to detention
- Fulfilling "reasonable course" of action

- Pursuing due process
- Principle of proportionality
- Rights-promoting practices to effectively eliminate the need and application of detention including community-based care models for MDR-TB, unique approaches to active case finding (such as ZAMSTAR), patient support initiatives, integrated treatment for HIV, Hepatitis C and drug treatment, etc

D) Access to new and effective diagnostics, treatment and vaccines,

This paragraph will discuss the need for research and innovations and the barriers to access to new tools, focusing particularly on some affected groups such as patients, MDR-TB patients, children. It will also outline for each challenge specific rights responses and action steps to be undertaken by each stakeholder group. Specific reference will be also made to the requirements as set out in the Oviedo Convention. Issues to be addressed:

- Lack of research on interventions and innovations
 - Key issues faced by key vulnerable group such as MDR-TB patients, children
 - Rights responses and action steps for each stakeholder group
- Barriers to access to new tools (*same structure as described above*)

VIII. Strategies for dissemination and use of this guidance by different stakeholders

- Roles of States, Ministries, NTPs
- WHO, UNAIDS, and UN system and intergovernmental bodies
- Multilateral organizations and donors
- Non-governmental organizations/civil society
- TB experts, advocates and partners
- Rights experts, advocates and partners
- Academic/educational institutions

IX. Monitoring, evaluation, review and operational research on implementation of the guidelines(for discussion)

- Whose responsibility?
- What mechanisms?
- Government
- Civil society partners and patient groups
- International partners
- Documentation and indicators
- Capacity building for applying a rights-based approach

X. Conclusions

Annex 1 : Consolidated tables on roles and responsibilities by group

Annex 2 - Key rights documents

- Universal Declaration of Human Rights (1948)
- International Covenant on Economic, Social and Cultural Rights (1966)
- International Covenant on Civil and Political Rights (1966)
- International Convention on the Elimination of All Forms of Racial Discrimination (1963)

- Convention on the Elimination of All Forms of Discrimination Against Women (1979)
- Convention on the Rights of the Child (1989)
- Convention on the Rights of Migrant Workers (1990)
- Convention on the Rights of Persons with Disabilities (2006)
- Convention Against Torture (1984)

Annex 3 - WHO, Stop TB and others' guidance focused on vulnerable groups and other rights-related issues

(to be further developed)

- Stop TB Strategy
- Global Plan to Stop TB, 2006-2015
- Stop TB Initiative: Guide for social mobilization: A rights-based approach to TB control, 2001
- *Patients' Charter for TB Care*
- Ethical Issues in TB Prevention, care and control
- Addressing poverty in Tuberculosis control
- Tuberculosis control in prisons
- Tuberculosis care and control in refugees and displaced populations
- Community involvement in Tuberculosis Care and Prevention (see also recent WHO-civil society consultation on TB control)
- WHO and UNAIDS guides to Universal Access to HIV prevention and treatment and UNAIDS Guidelines on HIV and Human Rights, (2006)
- Indigenous People's Stop TB Initiative action plan
- Human rights and tuberculosis: from prevention to transmission to treatment. J. Amon, UNAIDS Reference Group on HIV and Human Rights, 2009

Annex 4- Country case studies

Best practices and case studies could be used throughout the document to better illustrate key issues and/or could be published as a companion document depending on length.

Annex 5

Priority next steps and key events for action framework

Suggested next steps

- Describe TB and Human rights with friendly approaches for CCMS and programme managers
- Target or regularly brief CAT, UN Special Rapporteurs, CESCR, subcommittee for prevention of torture.
- Make contribution to UNGASS+10 and TB/HIV high level meeting
- WHA – anything on TB? Side event? Draft document?
- Access to Medicines Report for human rights council developed by special rapporteur on health – prepare statement to add TB.
- Send TF briefing note to programme managers, UNAIDS Country Offices and WHO Reps, etc.
- Develop briefing note for special rapporteurs on TB
- Support UNOHCHR office participation
- Develop newsletter re: TF activities.
- Build in M&E for human rights approaches from the outset.
- Compile on-line library of resources with links to already existing work
- Reaffirm Sirucusa Principles using WHO's statement
- Call for the endorsement of the Patients' Charter as a rights document
- Develop mailing list to share content.
- Assess HIV stigma index – very Africa focussed and look into adapting for TB.
- Before end November, book symposium/workshop/side event/abstracts for 2011 Union meeting.
- April - TF to have a note prepared on status of the TF and possibly Patient Charter for Stop TB Coordinating board meeting in DC.

Draft Calendar of related events 2011

- UNAIDS Human Rights reference group meeting (15-17 March, 2011 - Geneva)
- 24th March World TB Day, new WHO report on MDR treatment access progress
- UN Special Rapporteur on Health and Human Rights meetings March, June & September; Access to Medicines Report for human rights council developed by special rapporteur on health – prepare statement to add TB (*still to clarify*); Meeting with special rapporteur on torture - and others - set dates
- 31 March - 1 April Stop TB Coordinating Board meeting in DC – submit meeting report for their information, and encourage endorsement of Patient's Charter
- Meeting of Ministers of Southern Africa re TB, mining and cross-border issues -should have TF representation (date to be set)
- 5-6 May - Next Task Force meeting in Geneva to discuss draft policy framework
- 20-22 June - Draft policy framework to WHO STAG-TB
- Consultation in Kenya on patient detention cases - Spring, 2011 (tent:)
- Sept 2011 Regional committee meeting - 5 Year Plan to Combat MDR and XDR TB in Europe. 6-8 December planning meeting followed by web consultation.
- Special session on human rights & ethics 6th-8th September 2011
- 2011 Union Conference for symposium, abstracts for case studies, draft documentation, finished products and outline of session. Invite UN High Commissioner on Human Rights for plenary session?

- IAS Pathogenesis Conference July, Rome. NTP managers meeting.
- Global Fund – Lucica Ditiu consultations??