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MINISTRY OF HEALTH AND SOCIAL
SOLIDARITY**

Conference and Workshop

**Addressing Ethical Issues in
Tuberculosis Programmes
with a Special Focus on
Social Determinants**

**Athens, Greece
10-12 May 2010**

MEETING REPORT

Keywords

TUBERCULOSIS, PULMONARY – PREVENTION AND CONTROL
HEALTH PLANNING – ETHICS
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Executive Summary

On 10-12 May **2010** the National School of Public Health of Greece, the WHO Departments of Ethics, Equity, Trade and Human Rights and Stop TB, and the WHO European Regional Office, with additional financial support from the Hellenic Centre for Disease Control and Prevention as well as the Hellenic Ministry of Health and Social Solidarity, organized jointly in Athens a Conference and Workshop on “Addressing Ethical Issues in Tuberculosis Programmes with a Special Focus on Social Determinants”. The Conference was attended by over 100 participants, from 11 (Eastern) European and Central Asian countries and from Greece. The objectives of the meeting were:

- to raise awareness of ethical issues in TB care and control, with a focus on social determinants and equitable access to care, human rights, and legal aspects.
- to train NTPs in how to detect and address these issues in their national programmes.
- to produce concrete suggestions for implementation strategies regarding ethics, human rights, and social determinants at a national level.

The main outcomes of the meeting, which was not only the first of its kind in the Region, but also the first on Ethics and Social Determinants of Health (SDH) of TB, can be summarized as follows:

- A clear need was expressed for raising more awareness at all levels about the ethics dimension of TB control and the need to tackle social determinants
- Existing guidance documents have to be adapted to the national context
- Development of guidance on SD and TB, namely guidance on social factors and health including housing, finance and internal affairs sectors
- Need for further research and studies on SDH and TB
- Need for training and for the establishment of a network on TB, SDH and ethics
- Request for WHO (expressed by many countries) to provide country support in ethics and SDH, including in-country workshops for more senior level representatives from government about the importance of tackling the social determinants of TB.
- Request for WHO to provide support on developing laws and regulations in TB and infectious disease control
- WHO should emphasize the importance of involvement of civil society and vulnerable groups, in particular migrants, for TB control
- WHO should consider the need for integrated programmes, for ex. for TB and alcohol abuse
- Need of developing good material for education, communication and social mobilization
- Need for WHO and countries to pay attention to the ethical issues and social determinants when reviewing national TB programs
- Regular follow up with participants on actions since the workshop at 6 months intervals
- Holding an annual workshop on TB, SD and ethics: This would be the forum for annual exchange and updates and be hosted in some of the other participant countries.

Introduction

The provision of health care in a framework of respect for the individual and the fundamental ethical principles which apply to the practice of modern medicine, must constitute the common denominator behind all health policy strategies, including treatment of Tuberculosis. Tuberculosis (TB) prevention, care and control raise important ethical and policy issues that need to be adequately addressed. These concerns have been accentuated by the problem of multidrug-resistant TB (MDR-TB) and, most recently, by the emergence and spread of "extensively" drug-resistant TB (XDR-TB) which is especially difficult to detect and treat. A particular issue of ethical concern is that TB is a disease of the poor and vulnerable, and difficulties remain in reaching equitable access to TB services. In order to achieve success in TB programmes, the underlying social determinants which are driving the TB epidemic have to be identified and addressed through inter-sectoral action.

After an extensive consultative process, the WHO Secretariat and the Task Force is finalizing the WHO guidance document: "Guidance on Ethics for TB Care and Control Programmes". At the same time, in line with the findings of the Commission on Social Determinants of Health (SDH) and a related resolution of the World Health Assembly, WHO is working with Member States to support TB programmes in identifying and addressing the upstream causes and social determinants of disease.

The idea for the organization of a joint activity between WHO and the National School of Public Health (NSPH) of Greece was based on the need to educate and train representatives/key persons of National TB Programmes in Europe in using and adapting the WHO Guidance on Ethics and SDH. The National School of Public Health of Greece, since its establishment in 1929, has played and continues to play a major role in the Public Health of the Balkan Region and has often hosted national and international conferences, symposia and educational seminars.

Meeting objectives

Taking into consideration the great range of concerns regarding the ethics of TB prevention and treatment, the need to support governments and other stakeholders to implement these programmes in an ethical manner, and the need of health care systems to work in partnership, the objectives of this Conference were formulated in the following way:

- To raise awareness of ethical issues in TB care and control, with a focus on social determinants and equitable access to care, human rights, and legal aspects.
- To train NTPs in how to detect and address these issues in their national programmes.
- To produce concrete suggestions for implementation strategies regarding ethics, human rights, and social determinants at a national level.

Organisation

The meeting was organized jointly by the National School of Public Health of Greece, the WHO Departments of Ethics, Equity, Trade and Human Rights and Stop TB, and the WHO European Regional Office, with additional financial support from the Hellenic Centre for Disease Control and Prevention as well as the Hellenic Ministry of Health and Social Solidarity. The working languages of the meeting were English and Russian.

Participants

The Conference day was attended by over 100 participants, from 11 (Eastern) European and Central Asian high multidrug-resistant TB burden countries of the WHO Euro Region and from Greece.

The Workshops of days 2 and 3 were restricted to 27 participants from these countries.

Programme

Day 1 - Conference

The meeting was opened by Prof. J. Kremastinou, Department of Public Health of the National School of Public Health, Prof. J. Kyriopoulos, Dean of the National School of Public Health, Prof. J. Papadimitriou, Chair of the National Bioethics Commission of Greece, Prof. G. Saroglou, President of the Hellenic Centre for Diseases Control, Dr. P. de Colombani, Medical Officer TB of WHO-Regional Office for Europe, and Dr. A. Dimopoulos, General Secretary of Public Health of the Ministry of Health and Social Solidarity of Greece.

In the first session, Dr. Jaramillo of WHO's Department of STB gave an update on the Global TB control strategy, stressing the urgency for action created by the emergence and spread of MDR and XDR. In order to achieve sustainable success in TB control, he underscored the necessity to look beyond the traditional medical approach and to address the root causes of the disease and the ethical issues raised by TB. Dr. de Colombani followed with a presentation on European perspectives on TB control, in which he highlighted the magnitude of the TB epidemic and the relevance of addressing social determinants and ethical issues in European and Central Asian countries. He also discussed the role of economic poverty and recession, the fact that social determinants are not adequately addressed and the difficulty of vulnerable groups to reach TB services. Finally, Dr Gaga of the Athens Chest Hospital, Secretary Elect of the European Respiratory Society, gave a brief overview of TB control and care in Greece. She noted that while TB cases among Greek citizens were generally quite low, there were concerns about rising cases in migrant populations, including MDR/XDR. While universal access was guaranteed, the difficulties lay in case detection and ensuring patient adherence.

In the second session, Dr Garani-Papadatos from the National School of Public Health of Greece gave an introduction to bioethics and public health ethics. Then Dr Reis of WHO's Department of

Ethics, Equity, Trade and Human Rights presented WHO's work in developing the first guidance document on Ethics of TB control and care. He elaborated on the broad stakeholder consultation and highlighted the main issues raised in the document.

In the subsequent session, Prof. Martin of the University of Hertfordshire, UK, and the Chinese University of Hong Kong elaborated on the human rights, legal and ethical aspects of public health measures in TB control. She started with a general statement regarding the problematic content of most legislative texts on public health measures which, despite biomedical developments of the last decades, often continue to reflect obsolete scientific and social attitudes towards the treatment of infectious diseases. She then referred to recent examples in the UK, Ireland and Hongkong in order to discuss the difficulties countries face in dealing with measures to protect the public's health in the face of infectious disease threats, such as SARS, influenza and TB. In particular, she discussed issues such as involuntary isolation and the crude dichotomy between detainment and treatment, and how different legislations deal with these, through the existence of four different models (authoritarian, moderate, preventive and laissez-faire approaches). Professor Martin referred especially to the European Convention of Human Rights (in particular to articles 3,5, 6 and 8) and to the jurisprudence of the European Court of Human Rights, evoking relevant cases.

Prof Botnaru, Director General of the Phthysio-pneumology Institute of Moldova made a brief presentation on the situation in Moldova, outlining the epidemiological context, but also highlighting the importance of social determinants for TB. He stressed the importance of receiving support in discussing ethical and legal issues of isolation and drafting laws that comply with international ethical and human rights standards.

In the fourth session, Dr Vidalis discussed the ethical aspects of TB research, drawing a morally salient distinction between research and resistance surveillance. He outlined the internationally agreed principles governing biomedical research, stressing the importance of informed consent and the role of local ethics committees as guarantees but mentioning also the obstacles towards a valid informed consent between different cultures and in particular in developing countries (illiteracy, therapeutic misconceptions, proxy consent). He made special reference to issues such as placebo use, stigmatization and the tension between community involvement and privacy, the latter being a western concept encouraging in certain cases the isolation of the person from the community. Dr Vidalis concluded by saying that the heart of TB ethics lies in the attempt to *remove it from the shadow*.

Dr. Piret Vikklepp, Head of TB Registry of the National Institute for Health Development in Estonia, reported on the situation in Estonia. She stressed the importance of alcohol as a social determinant for TB and called for integrated TB and alcohol abuse treatment programmes. She mentioned that

involuntary isolation of TB patients was covered in Estonia by a law on infectious diseases which is only applied in extreme circumstances.

In the next session, Anand Sivasankara Kurup from the Social Determinants of Health (SDH) team at WHO gave a presentation on the Global findings on TB and SDH. He first introduced WHO's work on SDH and then spoke about the evidence at a global level. Dr de Colombani, on behalf of Sarah Simpson of the WHO-EURO Venice Office, then followed with a presentation on how to translate the global findings within the European region and countries.

In the final session of the conference, Dr Jeff Blackmer, Executive Director of Ethics at the World Medical Association, spoke about the ethical obligations and rights of health care providers and TB patients. He discussed the limits of the duty to care and the issue of risk to one's health and underlined the importance of education and protective measures for health care workers caring for infectious disease patients.

All sessions allowed some time for discussion, and the public participated very actively in raising questions for the speakers and making comments. In particular, the issue of involuntary isolation, health care worker's safety and corresponding duties, and social determinants raised a lot of interest in the audience.

Day 2 - Workshop on Ethics and TB

The workshop days (2+3) were restricted to 27 participants, in order to guarantee a good exchange and discussion in small working groups. The focus of day 2 was on ethical issues of TB. Three working groups each discussed three different case studies, which were specifically developed for this meeting. The cases were designed in a way to highlight ethical dilemmas that arise in TB programmes and clinical practice, to deepen the appreciation of participants for these difficult issues and to provide them with ways of resolving them. In between the group work sessions, participants reported back on their discussions to the plenary. The main issues resulting from the discussions were the following:

Case study 1: Isolation

The discussions revolved around the dilemma between public health interests and individual rights which can exist when a patient is infectious and not willing to be isolated. Participants agreed that involuntary isolation should be considered as the last resort, applied only when every other means have been tried but failed. In addition, when isolation or detention are to be employed, conditions and limits of such measures should be explicit, and due process followed. Some suggested that programmes should strengthen social support and even consider financial compensation to TB patients' family in order to enhance compliance with the measures.

Case study 2: TB research and surveillance

Participants discussed the grey area between routine public health surveillance and survey/research projects, and the corresponding ethical standards. There was general agreement that for research projects, participants should give informed consent. Moreover, drug resistance surveys should only be carried out, when there is also a plan to start adequate treatment programmes.

Case study 3: Obligations of Health Care Workers

In general, participants agreed on a strong duty to care of health care workers, as they knew the risks when they chose the profession, and have the knowledge of how to protect themselves. One of the major problems identified by the participants was the frequent lack of basic infection control measures in hospitals. In addition, some countries reported a lack of specialized TB doctors and nurses, and sometimes low staff morale due to low payment and some degree of stigmatization. Participants agreed that the health system and health care institutions have a strong obligation to provide the necessary training and adequate infection control to prevent infections of personnel.

Day 3 - Workshop on Social Determinants of Health

Ms Sarah Simpson first introduced the objectives of the workshop, which was followed by a Graffiti wall exercise on what creates health and whether participants agreed that tackling the social determinants of health was part of their role and function.

The objectives of the workshop were:

- To provide examples of action that can be taken
- To move from general statements to specific examples of possible action
- To identify enablers & challenges to acting
- To set out some principles for action
- To identify areas for enhanced technical assistance

This was followed by a group discussion between the participants in two groups, which were facilitated by Dr Pierpaolo de Colombani and Dr Knut Lonroth. **Working Group 1** focused on **migration**. The challenges of migration were seen from two perspectives (a) the country receiving migrants and (b) the country from which migrants have come. Participants were asked to identify existing but also additional actions that are being taken in recipient countries and in countries of origin to tackle the impact of migration for TB control. **Working Group 2** focused on **housing** and was asked to identify past and current actions that have / are being taken to improve housing in countries. The group also discussed and identified additional actions that should be taken in the future. Both working groups were asked to consider the following levels in identifying current and future action to be taken:

1. **Public health programmes:** improve management of co-morbidities (HIV, diabetes, etc.); interventions for risk populations (PLWH, homeless, prisoners, etc.); collaboration with other health programmes.
2. **Health system:** strengthening health system to improve its capacity in addressing all the above risk factors.
3. **Beyond health system:** addressing “upstream” social determinants by improving social, economic and environmental conditions of TB patients/families; coordination with other sectors; advocacy for social changes.

After the group discussions, Ms. Sarah Simpson made a short presentation on why and how to address social determinants of health, taking the participants through the framework developed by the TB programme in the Priority Public Health Conditions Knowledge Network, as well as arguing for the economic benefit of addressing social determinants of health. She also summarized the findings from the Graffiti wall exercise. Most participants took a comprehensive approach highlighting the need to address socio-cultural aspects of tuberculosis, and many are supposed to address social determinants of health in their daily work.

The presentation was followed by a rich discussion on social determinants and TB. The participants recognised that health is created mostly outside the health sector, but when it comes to tackling those social determinants, all are struggling for what they can do tangibly: (a) in working with other sectors; and (b) in their work within the health system. For example there is considerable scope for improving how the health systems action through better integration across health programmes to tackle co-morbidities and ensuring equity of access to basic services. The NTPs are overwhelmed to respond to the growing demands of early detection and treatment. There are a number of initiatives for working across programmes and sectors in Europe. For example, in Bulgaria, the TB and HIV/AIDS programmes are intensively collaborating, and in Romania there is a programme aiming to generate awareness among the Roma community and to increase their intake of health services. There are also quite a lot of potential entry points for action on SDH. For instance, in Greece, where TB burden among immigrants is high, working with the immigrants in camps and working with the officials in the immigration and law enforcement department for early detection and treatment are excellent entry points to address SDH and to improve health outcomes. Global issues require global solutions, and EU-wide policies on addressing upstream determinants of TB would be more effective. There is lack of good examples of tackling upstream social determinants of TB in the context of EU and a consequent need to encourage documentation and sharing of experiences in a way that is useful (i.e. being able to generalize from examples) and can be used to influence policy making. The network of people working on TB and social determinants issues could be one option.

Final plenary session

In the final plenary session, Andreas Reis first drew a few conclusions from the discussions on ethical issues during the first day, followed by remarks by Sarah Simpson on the discussion of SDH and TB. Then Andreas Reis and Pierpaolo Colombani gave the floor to participants of the meeting to give their feedback and to present ideas for implementation and potential needs of countries for support. The country representatives gave a very positive feedback from the meeting. Dr de Colombani thanked the participants for their valuable and positive feedback and outlined a few next steps. He mentioned the meeting of European National TB Managers in The Hague (31 May - 3 June) which would be an important opportunity to continue and deepen the discussion with sessions both on SDH and on ethics and human rights issues.

Dr Reis then briefly mentioned the next steps regarding the WHO Guidance Document on Ethics and TB, which will be published and disseminated within the next few weeks. He then thanked again the Greek organizers for their excellent collaboration and the participants for a very active participation and for engaging in open and constructive discussions in the meeting.

Finally, Dr Garani-Papadatos thanked the national nominees, Professor Kremastinou and her colleagues at the Department of Public Health of the NSPH as well as colleagues from other

Departments, the Hellenic Center for Disease Control, the WHO collaborators and all the participants.

Main outcomes of the meeting:

- A clear need was expressed for raising more awareness at all levels about the ethics dimension of TB control and the need to tackle social determinants
- Existing guidance documents have to be adapted to the national context
- Development of guidance on SD and TB, namely guidance on social factors and health including housing, finance and internal affairs sectors
- Need for further research and studies on SDH and TB
- Need for training and for the establishment of a network on TB, SDH and ethics
- Request for WHO (expressed by many countries) to provide country support in ethics and SDH, including in-country workshops for more senior level representatives from government about the importance of tackling the social determinants of TB.
- Request for WHO to provide support on developing laws and regulations in TB and infectious disease control
- WHO should emphasize the importance of involvement of civil society and vulnerable groups, in particular migrants, for TB control
- WHO should consider the need for integrated programmes, for ex. for TB and alcohol abuse
- Need of developing good material for education, communication and social mobilization
- Need for WHO and countries to pay attention to the ethical issues and social determinants when reviewing national TB programs
- Regular follow up with participants on actions since the workshop at 6 months intervals
- Holding an annual workshop on TB, SD and ethics: This would be the forum for annual exchange and updates and be hosted in some of the other participant countries.

Annex I: List of Participants

National School of Public Health

Kourea-Kremastinou Jenny

Dept of Public and Administrative Health
Athens, Greece

Pavi Elpida

Dept of Health Economics
Athens, Greece

Garani-Papadatos Tina

Dept of Public and Administrative Health
Athens, Greece

World Health Organization

de Colombani Pierpaolo

Medical Officer TB
Copenhagen, Denmark

Reis Andreas

Ethics and Health
Geneva, Switzerland

Gombogaram Tsogt

TB Coordinator for Central Asia

Simpson Sarah

Equity and Health
Venice, Italy

Jaramillo Ernesto

Drug Resistant TB
STOP TB Department
Geneva, Switzerland

Sivasankara Kurup Anand

Social Determinants of Health
Geneva Switzerland,

Lonnroth Knut

STOP TB Department,
Geneva, Switzerland

External Speakers - Facilitators

Blackmer Jeff

World Medical Association/Canadian
Medical Association

Lezhentsev Konstantin*

All Ukrainian Network of
People Living with HIV
Kiev, Ukraine

Gaga Mina

7th Resp. Med. Dept and Asthma Centre
Athens Chest Hospital, Greece

Martin Robyn

University of Heertfordshire
London, UK

Kriari Ismini
Unesco Expert in Bioethics
Greece, Athens

Vidalis Takis
Advisor to the National Bioethics
Committee
Athens, Greece

National TB Programmes

Armenia -

Dr Hovhanissyan Narine
Epidemiologist of the National TB
Programme, Central Office NTP Central
Office
Yerevan, Armenia,

Azerbaijan -

Dr Natavan Alikhanova
Deputy Head of NTP
Baku, Azerbaijan

Belarus -

Dr Liudmila Zhylevich
Department of Primary Care
Ministry of Health of Republic of Belarus
National TB Control Programme
Minsk, Belarus

Bulgaria

Dimitrova Anna
Specialized Donor - Funded Programmes
Directorate, Ministry of Health
Sofia, Bulgaria

Dr Vladimir Milanov
Chief Expert, Specialist on Lung Diseases,
Management of the Specialized Donor -
Funded Programmes Directorate, Ministry
of Health
Sofia, Bulgaria

Estonia -

Dr Piret Viiklep
Head Estonian Tuberculosis Registry
National Institute for Health Development
Tallinn, Estonia

Georgia -

Ms Eka Sanikidze
National Centre for Tuberculosis and Lung
Diseases
Tibilisi, Georgia

Kazakhstan -

Dr Nurkham Nazirova *
Division of TB Coordination
Department of Medical Aid Organization,

Ministry of Health of Kazakhstan
Astana, Kazakhstan

Kyrgyzstan -)

Dr Elena Kukhranova*
Department of Medical
Services Organization
Ministry of Health of Kyrgyzstan
Bishkek, Kyrgyzstan

Latvia -

Dr Velga Kuse*
State Agency, "Infectology center of Latvia",
Riga, Latvia

Lithuania -

Dr Edita Davidaviciene
National Tuberculosis and Infectious
Diseases University Hospital
Vilnius, Lithuania

Moldova -

Dr Victor Botnaru
Phthysiopneumology Institute "Chiril
Draganiuc",
Chisinau, Republic of Moldova

Russian Federation -

Dr Ekaterina Kormacheva*
Division of Specialized Development
Programmes
Department of Health Care Organization
and Public Health Development
Moscow, Russian Federation

Tajikistan -

Dr Shekhov Abdukarim*
National Center for TB Control
Dushanbe, Tajikistan

Ukraine -

Dr Olga Sakalska*
Social Dangerous Diseases Unit
Committee on HIV/AIDS and other Social
Dangerous Diseases
Kyiv, Ukraine

Uzbekistan -

Dr Bakhrom Muminov
National Counterpart on Tuberculosis
Department of Health Care and Prevention
Ministry of Health
Tashkent, Uzbekistan

GREECE

Adamidi Victoria

Health Visitor, "Sotiria" Hospital
Athens

Athanasiou Maria

Hellenic Centre for Diseases Control and
Prevention
Athens

Avgerinou Christina

University Hospital of Patras
Patra, Greece

Kavvalou Maria

Health Professional
Prefecture of Athens
Greece

Koletsis Patra

Athens, Greece

Koutiva Stavroula

Nurse at the Public Hospital of Calamata
Calamata, Greece

Lytras Theodore

Hellenic Centre for Diseases Control and
Prevention
Athens, Greece

Matsikas Nikolas

Hospital of Thiva
Thiva, Greece

Milionis Charalampos

General Hospital of Corinthos
Corinthos, Greece

Mitsaki Chrysanthi

Moraitou Emmanouela

Network and Social Support for Refugees,
Athens

Papagiannopoulou Aggeliki

Public Health Doctor, Public Health
Division
Ministry of Health and Social Solidarity
Athens

Polychronakis John

"Evangelismos" General Hospital
Athens, Greece

Spala Georgia

Hellenic Centre for Diseases Control and
Prevention
Greece

Tachopoulou Afrodite

Health Inspector
Pallini, Greece

Thanassias Efthimios

University Hospital of Larissa
Larissa, Greece

Theologi Vassiliki

"Aretaieio" University Hospital
Athens, Greece

Troupi Koukoutsis Irini

Health Professional, General Hospital of
Kifissia
Kifissia, Greece

Tzannetakou Antonia

Health Professional
Prefecture of Athens
Athens, Greece

Zerva Loukia

Ministry of Health and Social Solidarity
Penteli, Greece

Dept of Microbiology, "Attiko" Hospital
Athens, Greece

Secretariat (NSPH)

Xiki Joan
Athens, Greece

Miloni Kelly
Dept of Public and Administrative Health
Athens, Greece

Papadopoulou Tamara
Athens, Greece

Rapporteurs

Realpe Quintero Sandra
Interdisciplinary Humanities Center
(CIDEH)
Universidad de San Buenaventura
Cali, Colombia

Wang Ning
Department of Ethics, Equity, Trade and
Human Rights
WHO
Geneva, Switzerland

Free-lance Interpreters

Boulakovski Dmitri
Geneva

Kasimova - Zouchra Aikaterini
Athens

Erickson Julia
Geneva

Tsybenko Andrey
Moscow

Ilyukhin Vladimir
Moscow

* Unable to attend

Annex II: Programme



SCIENTIFIC CONFERENCE

ADDRESSING ETHICAL ISSUES IN TUBERCULOSIS PROGRAMMES WITH A SPECIAL FOCUS ON SOCIAL DETERMINANTS

Monday, 10th May 2010

09.00 – 17.30

**National School of Public Health
Auditorium**

196 Alexandras Avenue

DAY 1: Conference

8:30-9:00	Registration
9:00-9.30	Welcome and introductions Jenny Kourea-Kremastinou <i>Professor, Dept of Public Health, NSPH</i> John Kyriopoulos <i>Dean, NSPH</i> John Papadimitriou <i>Chair, National Bioethics Commission</i> George Saroglou <i>President, Hellenic Centre for Diseases Control</i> Pierpaolo de Colombani <i>Euro TB Focal Point</i> Antonios Dimopoulos <i>General Secretary of Public Health, Ministry of Health and Social Solidarity</i>
9:30-9.50	Update on Global TB control strategy Ernesto Jaramillo
9:50-10.10	European perspectives on TB control Pierpaolo de Colombani
10:10-10.30	TB control and care in Greece Mina Gaga
10:30-11:00	Coffee break
11:00-11.45	Introduction to public health ethics and bioethics T. Garani-Papadatos Discussion
11:45-12.15	Presentation of the WHO Guidance on Ethics of TB control and care Andreas Reis Discussion
12:15-13:30	Lunch
13:30-14.15	Human rights, legal and ethical aspects of public health measures in TB control Robyn Martin Victor Botnaru Discussion
14:15-15.15	Round Table: Ethical aspects of TB research and resistance surveillance Takis Vidalis Piret Viiklepp Discussion
15:15- 15:45	Coffee break
15:45-16.30	Social determinants of TB and equitable access to TB services Anand Sivasankara Kurup Pierpaolo de Colombani Discussion
16:30-17.00	The ethical obligations and rights of health care providers and TB patients Jeff Blackmer
17:15	Concluding Discussion

DAY 2+3: Workshops on Ethics and Social Determinants

TIME	TOPIC	FACILITATORS
11 May	Workshop on TB and ethical issues	Blackmer, Martin, Pavi, Vidalis, Kriaris
9:00	Plenary: Introduction to case studies Break-out groups: case study 1 Ethical, legal and human rights aspects of public health measures in TB control	
10:30-11:00	Coffee break	
11:00	Plenary discussion of case study 1	Prof Robyn Martin
12:00	Break-out groups: case study 2 Ethical aspects of TB research and resistance surveillance	
13:00-14:00	Lunch break	
14:00	Plenary discussion of case study 2	Dr Takis Vidalis
15:00	Break-out groups: case study 3 The ethical obligations and rights of health care providers and TB patients	
16:00-16.30	Coffee break	
16.30	Plenary discussion of case study 3	Dr Jeff Blackmer
17:30	End of day 2	
Evening	Acropolis Museum tour and reception hosted by the National School of Public Health	
12 May	Workshop on TB and social determinants	
9:00-9:10	Plenary: Introduction and overview of the workshop on social determinants of TB	Ms Sarah Simpson
9:10-10:10	Plenary: Knowledge, attitudes and practices about health and TB: a. Graffiti wall exercise b. Discussion in the 2 groups about the answers to the preparatory questions sent to participants before the meeting - 25 min. discussion & 5 min. for rapporteur c. Feeding back to plenary from 2 groups and summary of key points from graffiti wall.	Ms Sarah Simpson, Dr Pierpaolo de Colombani, Dr Anand Sivasankara Kurup, Dr Knut Lönnroth
10:10-10.30	Plenary: Setting the scene: some principles for taking action on social determinants of TB	Ms Sarah Simpson
10.30-11.30	Working groups 1 and 2	Dr Pierpaolo de Colombani, Dr Anand Sivasankara Kurup, Dr Knut Lönnroth
11:30-12:15	Coffee and sandwiches break	
12:15-13:15	Plenary: Feeding back with presentation by the working groups 1 and 2, followed by discussion	Dr Elvida Pavi
13:15-14:00	Final plenary on ethical issues and social determinants of TB: <ul style="list-style-type: none"> • The way forward & implementation • discussion and conclusions 	Ms Sarah Simpson, Dr Pierpaolo de Colombani, Dr Anand Sivasankara Kurup, Dr Knut Lönnroth, Dr Andreas Reis, Dr Tina Garani
14:00	End of meeting	