



# ETHICAL ISSUES IN TUBERCULOSIS PREVENTION, CARE AND CONTROL

## BACKGROUND

In 2013, over 9 million people fell ill and about 1.5 million people died of tuberculosis (TB). Although there have been some major achievements in controlling TB, it **remains a crucial health threat**, in particular to the most vulnerable populations in the developing world. The problem has been accentuated by the emergence of new drug-resistant strains of TB (MDR-TB and XDR-TB), which are especially difficult to detect and treat.

Prevention, care and control of TB raise not only technical, but also **important ethical and policy issues** that need to be adequately addressed. For instance, recent cases of involuntary detentions of people with TB in several parts of the world have brought up the question of how to balance individual rights and liberties against the protection of public health.

Recognizing the current lack of ethical guidance, WHO established a **Task Force on Addressing Ethical Issues in TB Care and Control Programmes** in August 2008. Based on an initial draft elaborated by the Task Force and broad consultations with other experts and stakeholders, a guidance document entitled "**Guidance on Ethics of TB Prevention, Care and Control**" was published in November 2010.

### FREQUENT ETHICAL DILEMMAS IN TB CARE:

- Do patients have the right to refuse treatment?
- Is it ever legitimate to isolate contagious patients against their will?
- Do health care workers have an obligation to care, even when it involves significant health risks?
- Should a patient's TB status ever be disclosed to third parties against his/her will?
- Should financial incentives be offered to increase adherence to treatment?
- Should patients be diagnosed in the absence of adequate treatment?
- Is it justifiable to administer substandard drugs where no alternative is available?



## MAJOR ETHICAL CONSIDERATIONS ASSOCIATED WITH TB

- **Governments have a responsibility to provide free TB Care**

Governments have an ethical responsibility to provide free and universal access to diagnosis and adequate treatment of TB. This obligation is grounded in their duty to fulfil the **human right to health**. Not only does TB treatment significantly improve the health condition of individuals, stopping the spread of a highly-infectious disease also benefits the broader community.

Governments also have the same **duty to provide access to M/ XDR-TB care**, even if many countries still have to scale up treatment. In the absence of appropriate drugs, it is still recommendable from a public health perspective to provide testing, as long as the patient consents.

- **Patients need to be fully informed and counselled about their treatment**

Individuals have a **right to bodily autonomy**, therefore patients undergoing TB testing and treatment should receive complete and accurate information about the risks, benefits and alternatives available to them. Furthermore, a proper understanding of the disease is most likely to increase adherence to treatment.

- **Health care providers have an obligation to support patients to complete therapy**

There are several ethically sound strategies to support patient's ability to adhere to treatment, including directly-observed therapy and the use of appropriate financial or other incentives. It is crucial that **patients should be engaged as partners in the treatment process**, respecting their autonomy and privacy. If many patients have problems with adherence, this suggests the system has failed in providing a person-centred approach.

- **Health care workers have obligations to provide care, but also a right to adequate protection**

**Health care workers have an ethical obligation to care for their patients**, even if doing so involves some degree of risk. However, they should not be expected to assume risks that result from inadequate conditions to provide care; **governments and health-care institutions must provide the necessary goods and services** to allow for a safe working environment. Also, health-care workers who are at heightened risk of contracting TB themselves, such as those who are HIV posi-

- **Involuntary isolation should never be a routine component of TB programmes**

In general, **TB treatment should be provided on a voluntary basis**, engaging the patient in the treatment process and respecting his/her autonomy. If a patient refuses treatment, this is likely to be due to insufficient counselling or lack of treatment support. In very rare cases, where all efforts to engage a patient to adhere treatment fail, the rights of other members of the community might justify efforts to isolate the contagious patient involuntarily. However, **isolation should always be used as a very last resort** and it should not include forced treatment if the patient refuses it.

- **Research on TB is necessary and should be conducted in an ethical manner**

Developing an enhanced evidence base for TB prevention and treatment is necessary in order to improve the standard of care and prevention (e.g. developing new drugs or understanding the social determinants of the disease). However, it is indispensable that **research be guided by the principles articulated in international guidelines for biomedical research** involving human subjects (such as the CIOMS & Declaration of Helsinki). In general, research should always be most concerned about the dignity of the subjects and results should lead to a benefit of the affected population.

WHO's Department of Knowledge, Ethics, and Research (KER) and the Global TB Programme (GTB)

## Guidance on ethics of tuberculosis prevention, care and control



## The END TB STRATEGY

### PRINCIPLES

1. Government stewardship and accountability, with monitoring and evaluation
2. Strong coalition with civil society organizations and communities
3. **Protection and promotion of human rights, ethics and equity**
4. **Adaptation** of the strategy and targets at country level, with global collaboration

## FURTHER LINKS AND DOCUMENTS

WHO's Ethics and Health website: <http://www.who.int/ethics/en/index.html>

WHO's activities on Ethics & TB: <http://www.who.int/tb/challenges/mdr/ethics/en/index.html>