

ETHICAL ISSUES IN TUBERCULOSIS

PREVENTION, TREATMENT & CARE

BACKGROUND

- In 2015, over 10.4 million people fell ill and about 1.8 million people died of tuberculosis (TB) including 0.4 million among people with HIV.
- Major achievements have been made in the fight against TB with 49 million lives saved since 2000.
- However, TB remains a crucial health threat, in particular to the most vulnerable populations all over the world.
- Development of, and active transmission of drug-resistant strains of TB (MDR-TB and XDR-TB), add to the challenge as these are especially difficult to detect and treat.
- Prevention, diagnosis, treatment and care of people with TB raise not only technical, but also important ethical 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.
- The World Health Organization's (WHO's) End TB Strategy and the UN Sustainable Development Goals (SDGs), which target ending the TB epidemic by 2030, call for due attention to equity, human rights and ethics. "Protecting human rights, ethics and equity" is one of the four key principles of WHO's End TB Strategy. The SDGs agenda itself is inspired by a simple motto: "leave no one behind".

WHO GUIDANCE ON ETHICS TO END TB

- WHO has released new guidance on TB Ethics entitled "Ethics Guidance for the implementation of the End TB Strategy" to help ensure that the implementation of the End TB Strategy is in line with sound ethical standards.
- The goal of this guidance document is to assist those working towards ending TB by proposing practical answers to key ethical questions and enabling patients, families, civil society, health workers and policy makers to move forward and address current challenges. The document includes special sections on key populations, such as children, migrants, and prisoners, as well as on digital health technologies, screening, surveillance and research.



WHY ARE ETHICS IMPORTANT

- Ethics and human rights are at the heart of a **humane, patient-centred approach to TB care**.
- Addressing ethical issues is crucial for **winning the trust and cooperation of patients** and care providers - essential for a successful TB programme. For example, engaging, educating and supporting patients are ethical responsibilities of health care workers which are directly related with a positive treatment outcome.
- TB is a disease of poverty. A focus on **social justice** means caring for the most vulnerable and marginalized and addressing the social determinants which underlie the TB epidemic.
- Providing **health care workers** with adequate protections is a key factor in having a healthy and committed work force.
- Ensuring adequate treatment for **migrants** is grounded in the ethical duty to care for the most vulnerable, "leaving no one behind", and also in the interest of the populations of host countries.
- As we expect most **prisoners** to reintegrate back into the community –adequate care and treatment for them is an ethical obligation and a public health imperative.
- Access to diagnosis and treatment for **children** needs to be expanded to reach all in need.
- **TB research** has been grossly underfunded. The international community and donors have an ethical obligation to increase investments in this area, to help save lives.

For more information please access:

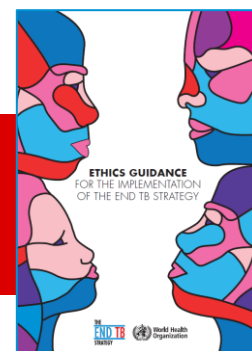
WHO's website on Global Health Ethics:

www.who.int/ethics/en/index.html

WHO's website on Ethics and TB:

www.who.int/tb/areas-of-work/treatment/ethics/en/

MAJOR ETHICAL CONSIDERATIONS WHEN ENDING THE TB EPIDEMIC



Governments have an ethical responsibility to implement services based on the End TB Strategy

Governments have an **ethical responsibility to ensure free and universal access to diagnosis, treatment and care of TB**. They also have to ensure that health care workers operate in a safe environment; patients are enabled with proper support to fulfil their responsibilities. These obligations are 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 the disease also benefits the broader community. Governments also have the same duty to **provide access to MDR-TB care**, even if many countries still have to scale up treatment. In the absence of appropriate drugs, testing still can provide benefits to patients and public health.

People need to be fully informed and counselled about their TB situation

Individuals have a right to bodily autonomy, therefore people undergoing TB testing and treatment should receive complete and accurate information about the risks, benefits and alternatives available to them; and access to all means which enable informed adherence to treatment.

Health care providers have an obligation to support patients to complete therapy and offer all possible treatment options

Any tool to ensure adherence to treatment, including **directly-observed therapy**, should be based on a **patient-centred approach**, so that values and needs of patient guide the care delivered, respecting autonomy and privacy. Compassionate use and expanded access programmes are ways of ensuring that patients have access to all possible resources in treating their TB.

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 positive, may be exempted from their duty to care.

Involuntary isolation should never be a routine component of TB programmes

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 to 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.

Prioritizing of TB research to be conducted in an ethical manner

Continued development of an enhanced evidence base for TB diagnosis, prevention, treatment and care is urgent in order to continue improving the standards of TB care, including development of point of care tests, new drugs, and vaccines. It is **imperative that research be guided by the principles articulated in the international guidelines for biomedical research** involving human subjects, and that **data is immediately shared** without any delay for national and global policy making, so that affected populations benefit and lives are saved.

FREQUENT ETHICAL ISSUES IN TB CARE

- Should patients be diagnosed in the absence of adequate treatment?
- Should the status of people with TB be disclosed to third parties against their will?
- Do patients have the right to refuse treatment?
- Should treatment be delivered under direct-observation in the absence of a patient-centred approach?
- Is it ever legitimate to isolate contagious patients against their will?
- Should children be hospitalized just to deliver TB treatment?
- Should palliative care be offered to people with MDR-TB?
- Do health care workers have an obligation to care, even when it involves health risks?
- Should researchers retain data needed for public health policy until it is published in peer-reviewed journals?