



**Ethics of Tuberculosis
Prevention, Care and
Control**

**MODULE 5: INFORMATION
COUNSELLING AND THE ROLE OF
CONSENT**

[INSERT SPEAKER NAME
DATE &
LOCATION HERE]

Insert
country/ministry
logo here

Objectives

Upon completion of this module, you will be able to:

- Describe the ethical justification for providing patient and counselling
- Explain the role and meaning of informed consent

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Ethical justification for providing information

- People have the right to know what is being done to their bodies and why
- Helps patients understand TB, how it is spread, and the options for treating it, making it more likely that individuals will adhere to treatment
- Providing full information about TB treatment helps instill trust in system, leading to higher level of respect in community

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Kind of information provided

- TB Testing
 - Basic information about the nature of TB and why they are being tested
- Individuals offered TB treatment
 - Information about the risks and benefits of the proposed interventions, including the role of traditional medicine
 - Importance of completing the full course of treatment
 - Infection control measures
 - Available support to help patients complete the full course

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Ensuring provision of appropriate information

- Work with peer advocates and community leaders
- Suitable for individuals from diverse backgrounds:
 - Linguistic
 - Educational
 - Cultural

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PLENARY

Consider...

How do you provide relevant, appropriate and accurate information to patients?

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Informed consent

- Process of engaging patients as partners in the treatment process by giving them relevant information and an opportunity to make decisions for themselves
- Ethical aspect should not be confused with legal mechanisms
- **Fundamental ethical requirement of engaging patients as partners by ensuring that their decisions are voluntary and informed**

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Elements of informed consent

- Nature of the decision or procedure
- Reasonable alternatives to proposed intervention
- Relevant risks, benefits, and uncertainties related to each alternative
- Assessment of patient understanding
- Acceptance of the intervention by patient

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Informed consent in TB testing and treatment

- Usually no need for a specific process of informed consent to TB diagnosis
- Providers should seek the patient's informed consent to TB treatments
- No obligation for written consent forms or consent to treatment in writing

Providers must provide relevant information and seek the patient's agreement to undergo treatment

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Consent around diagnosis in absence of treatment

- For TB testing, a specific consent process is generally not required
- **However, implicit consent for diagnostic testing is premised on availability of treatment**
- In absence of treatment for drug resistant TB, consent is required for drug susceptibility testing:
 - Inform patient of risks and benefits of testing
 - Specifically ask about willingness to consent in the absence of treatment

When explicit informed consent is needed

Areas	Yes	No
TB Testing		✓
TB Treatment		✓
Drug-susceptibility testing in the absence of treatment	✓	
Research	✓	

World Health Organization. Guidance on ethics of tuberculosis prevention, care and control, 2010

Disclosure about process for contact notification: Mandatory case-reporting system

- Notification may trigger a public health intervention
- Determine identity of close personal contacts
- Contacts are notified of their risk of infection

Healthcare worker responsibility:

- Explain process to patients
- Seek to enlist patient's cooperation in identification and notification of contacts

Disclosure about process for contact notification:
No case-reporting or contact tracing system

- Patients should be encouraged to notify their contacts themselves
- TB programmes should provide assistance and support to patients

PLENARY

Think about...

Explore the reasons why a patient with TB would not want to participate in the process of contact identification and notification and generate possible solutions

Reason	Possible Solution

Non-disclosure of patient status

- Ethical and human rights standard is to protect the confidentiality of the patient
- Contact identification and notification CAN be carried out without disclosing name of the patient
- Non-consensual disclosure of the patient's health status to a third party violates the patient's right to confidentiality
- Disclosure of status can have significant impact on patient due to stigma and can impact patient's relationship with health care providers
- However:
 - Third party's right to life may be seriously threatened if patient has infectious TB, especially if it is a drug-resistant strain
 - Consider rights of the individual patient vs. rights of the patient's contacts/public

Justification for non-consensual disclosure*

*Non-consensual disclosure: informing a third party about a patient's status without his or her consent

- Guided by obligation to protect the lives of others
- Viewed as a last-resort option
- Only when there is a significant risk of infection to others if status is not disclosed and limited to those who need to know in order to protect their own health or health of others
- Public health authorities and TB programmes should develop clear policies governing non-consensual disclosure
- Patient notification to take place before any non-consensual disclosure is carried out

Provider obligations with treatment refusal

- Counsel about risks to both themselves and community
- Seek to understand the reasons for reluctance about treatment
- Work together to identify methods for overcoming concerns
- Should treatment refusal persist:
 - Inform patient that they could be subject to involuntary isolation or detention

PLENARY

What is your current practice in dealing with patients who have refused treatment?

Reason for Refusal	Potential Solution

Possible solutions for dealing with refusal to be treated

PLENARY

Reason for Refusal	Potential Solution
Concerns regarding disclosure	Reassure patient that all information is confidential Assess strength of family and social support Inform patient of need for contact tracing Encourage patient to discuss TB diagnosis and treatment with support structure
Misconceptions relating to treatment	Assess patient's knowledge, beliefs, and attitudes about TB and TB treatment Assess strength of family and social support Encourage patient to discuss TB diagnosis and treatment with support structure
Concerns regarding adherence	Discuss ability to take responsibility for adhering to TB treatment Assess strength of family and social support Encourage patient to discuss TB diagnosis and treatment with support structure



Day One Summary – 1

- Topics discussed today
 - Introductions: who we are, and our beliefs and practices round ethics and TB
 - Ethics assessment tool: examining our TB Programmes using an ethical perspective
 - Overview of ethical values and human rights
 - Obligation to provide access to TB services
 - Information counselling and the role of consent
- Questions or comments?

Day One Summary – 2

- Topics for tomorrow
- Review of any outstanding questions
- Supporting adherence
- Gaps between testing and treatment for drug resistant TB
- Health care worker rights and obligations
- Involuntary isolation and detention
- Research on TB care and control
- Putting it all together: developing strategies and approaches for improving ethical challenges or gaps in TB care: **Bring your completed Assessment Tool!**

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