

# **An ethical dilemma: diagnosis without treatment**

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# Outline

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- Relevant ethical principles
- Possible analogies
- What does the WHO guidance document on Ethics & TB say?
- Implications for practice

# Relevant ethical principles

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- Right to know
- Right not to know
- Duty to know and not infect others
- Protect individual rights and public health

# Weighing risks and benefits in promoting diagnosis

## Risks:

- Stigma
- Discrimination
- Anxiety
- Isolation?

## Benefits:

- Knowledge of status, life plans
- Prevention:
  - a) patient
  - b) immediate surrounding
  - c) public health
- Treatment ?

Goal: Maximize benefits, minimize risks

# Possible analogies

- Standard of care debate in research ethics
- Testing and counselling in genetic diseases:  
for ex., Huntington's disease
  - transmissible (hereditary, autosomal dominant)
  - incurable
  - would a single person still want to know?
- Debate over cervical cancer screening in the absence of treatment
- Debate over HIV provider-initiated testing & counselling in the absence of ART

# Ethical considerations in promoting provider-initiated HIV Testing & Counselling (T&C)

## T&C only when treatment and prevention available?

Which **minimum standard** of treatment, care and support should be available when implementing "provider-initiated T&C"?

- a) ART
- b) Treatment of OI and palliative care
- c) Counselling and psychosocial support
- d) Community, group, individual level prevention programmes with wide coverage and high intensity
- e) None

What does *availability* mean? Free at point of service?

After testing, the cost may preclude patients from treatment

# Provider-initiated HIV testing and access to ART

"A routine offer of HIV testing by health care providers should be made to all patients being (...) seen in clinical and community based health service settings where HIV is prevalent and antiretroviral treatment is available (injecting drug use treatment services, hospital emergencies, internal medicine hospital wards, consultations etc.) but who are asymptomatic."

***UNAIDS/WHO Policy Statement on HIV Testing, 2004***

"Although access to antiretroviral therapy should not be an absolute prerequisite for the implementation of provider-initiated HIV testing and counselling, there should at least be a reasonable expectation that it will become available within the framework of a national plan to achieve universal access to antiretroviral therapy for all who need it."

***WHO/UNAIDS Guidance on provider-initiated HIV testing and counselling in health facilities, 2007***

# What does the WHO guidance on Ethics & TB say?

- Ideally, all patients should undergo drug susceptibility testing, and have access to a tailored drug therapy.
- While countries are in the process of scaling up treatment, testing can be appropriate as an *interim* measure when no second- or third line drug is available, or when the only available treatment is substandard.
- Countries that implement diagnostic testing in the absence of treatment should do so only as a temporary measure, and should establish a timetable for when treatment for M/XDR-TB will be made available.

Guidance on ethics  
of tuberculosis prevention,  
care and control





# What does the WHO guidance on Ethics & TB say?

## Diagnosis in the absence of treatment can:

- Enable surveys to measure the magnitude of M/XDR-TB epidemic and plan capacity building to address the problem
- ensure that individuals with M/XDR-TB are not treated with regular drugs, contributing to protect the efficacy of anti-TB drugs
- help individuals make life plans, inform important behaviour regarding infection control
- guide decisions on TB management in congregate settings (hospitals, schools, prisons etc.)

# Implications for practice

- Building capacity for treatment from the start is an ethical obligation
- Importance of informed consent:  

Individuals should not be given diagnostic testing in the absence of treatment unless they have provided specific informed consent
- Involvement of communities and patient groups crucial



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