

# *Self-Study Modules on Tuberculosis*

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## **Confidentiality in Tuberculosis Control**

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Public Health Service**

**Centers for Disease Control and Prevention**

**National Center for HIV, STD, and TB Prevention**

**Division of Tuberculosis Elimination**

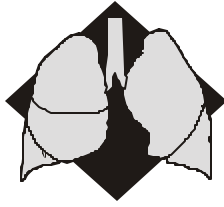
**Public Health Practice Program Office**

**Division of Media and Training Services**



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# Confidentiality in Tuberculosis Control

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## BACKGROUND

*In this module, you will learn what confidentiality means in the context of tuberculosis (TB) control. Confidentiality is an essential issue in many different aspects of TB control. Health care workers need to be aware of the confidentiality issues that are relevant to patient-health care worker encounters, as well as to the collection, management, and sharing of data gathered on TB patients. In the treatment of TB disease, the relationship between the patient and the health care worker is extremely important because of the serious consequences of treatment failure. If patient information is disclosed to unauthorized persons without the patient's permission, the patient may be stigmatized or experience rejection from family and friends, lose a job, or be evicted from housing. Moreover, the health care worker may lose the trust of the patient, which can affect adherence to TB treatment. Therefore, confidentiality — the responsibility to protect a patient's private information — is critical in TB control.*

*This module highlights specific situations in which a health care worker needs to consider and protect the rights of TB patients. It discusses general recommendations for developing trust with a patient, limiting disclosures, negotiating conflicts, and following due process. By using the recommendations in this module, you should be able to protect the confidentiality of your patients' personal information and help the program fulfill its responsibilities to the public.*

## OBJECTIVES

After working through this module, you will be able to:

1. Explain what confidentiality is, and why it is important to TB control.
2. List four serious consequences that may result from revealing personal information without the patient's permission.
3. Explain the patient-health care worker relationship and how it is like an agreement between two parties.
4. Define health care worker and third party, and explain the difference between these two terms.
5. Explain why trust is a key element in a successful patient-health care worker relationship and three ways to develop trust.



6. List four types of patient's rights and describe their purposes.
7. Describe how confidentiality is an essential issue in several of the core components of a TB control program.
8. Describe how confidentiality is important in the identification and management of TB cases and in ensuring adequate therapy.
9. Describe what should be done to protect a patient's rights during a contact investigation and screening for tuberculosis.
10. Explain how other program activities, especially those involving data collection and analysis, require measures to provide data security and protect confidentiality.
11. List the ways in which a patient's confidentiality can be protected in any situation: in an office, clinic, institution, or the field.



## NEW TERMS

Lists of new terms were introduced in each of the five core *Self-Study Modules on Tuberculosis* (Modules 1-5). Please refer to the core modules or their Glossary if you encounter unfamiliar terms related to TB that are not defined in this New Terms section.

Look for the following new terms in this module.

**authorization** – permission given by the patient to allow a third party to have access to the patient’s confidential information

**autonomy** – the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent

**confidentiality** – the protection of information revealed during patient-health care worker encounters, including all written or electronic records of these encounters

**consent** – acceptance or approval of what is planned or done; it involves voluntary agreement to an action, whether it is a treatment option or a diagnostic test; the patient-health care worker relationship is founded on the patient’s consent to the care being provided

**court order** – an order issued by a court mandating DOT or, in very rare cases, detention in a facility until treatment is completed

**disclosure** – the act of revealing or distributing personal information

**due process** – an established course for governmental activities or procedures, designed to safeguard the legal rights of the individual

**health care worker** – any member of a team of health professionals who care for and manage a TB patient, including physicians, nurses, outreach workers, hospital discharge planners, pharmacists, and social workers

**informed consent** – a patient’s written consent to a surgical or medical procedure or other course of treatment, given after the health care worker has informed the patient about the potential benefits, risks, and alternatives involved

**partner notification** – an activity conducted by HIV/AIDS programs to identify and counsel the sexual and needle-sharing contacts of HIV-infected persons; this notification is confidential and depends on the voluntary cooperation of the patient



**patient-health care worker relationship**– the basis for sharing information, communicating beliefs and feelings that affect care, and building trust in the value of the interaction

**patient-identifiable information**– information in which the identity of the patient is directly included or can be deduced

**privileged information** – personal information shared by the patient with his or her health care worker

**routine case reporting** – the required reporting of suspected or confirmed TB cases to a public health authority

**statement of disagreement** – a statement filed by the patient stating there is a disagreement with the health care worker or institution regarding the patient’s record

**third party** – a person or an organization not directly involved in the care of a patient’s health problem

**waiver** – a form that patients are often asked to sign to allow their health information to be used by third parties



# READING MATERIAL

## Introduction

.....  
Confidentiality involves the protection of information revealed during patient-health care worker encounters, including all written or electronic records of these encounters.

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.....  
It is the responsibility of the health care worker to protect the patient's private information and ensure that only those persons who need to know information have access to patient records.

.....

### Confidentiality

The protection of private patient information is commonly referred to as **confidentiality**. Confidentiality involves the protection of information revealed during patient-health care worker encounters, including all written or electronic records of these encounters. Confidentiality is an essential issue in many different aspects of TB control. Health care workers need to be aware of confidentiality issues that are relevant to patient-health care worker encounters, as well as to the collection, management, and sharing of information gathered on TB patients.

Health care workers should keep patient information in confidence and only divulge it with the permission of the patient except as otherwise required by law. It is the responsibility of the health care worker to protect the patient's private information and ensure that only those persons who need to know information have access to patient records. Only persons directly involved in patient care or public health activities should have access to patient information. Safeguarding patient information should be a priority for all members of the health care team.



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The TB patient has certain rights that must be respected and are often protected by legislation.

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The health department has a responsibility to protect the public's health using certain effective TB control strategies.

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Confidentiality is a very important issue in TB control because the diagnosis of TB disease is potentially damaging to patients. For some patients, a diagnosis of TB can lead to stigmatization or rejection by family, friends, and coworkers; the loss of a job; and possibly eviction from housing. There are some specific confidentiality issues that require special attention by health care workers working with TB patients:

- # The TB patient has certain rights that must be respected and are often protected by legislation
- # The health department has a responsibility to protect the public's health using certain effective TB control strategies
- # In the course of conducting TB control activities, some patient rights may be overridden in the interest of protecting the public's health (for example, an uncooperative, infectious patient may be quarantined until noninfectious)
- # Great care must be taken to ensure that patient rights — especially the right to privacy — are protected to the fullest extent possible so the patient-health care worker relationship is not compromised; this relationship must be strong enough to last throughout the time it takes a TB patient to complete therapy





**Study Questions 7.1-7.2**

**7.1. What is confidentiality and why is it important in TB control?**

**7.2. List four specific confidentiality issues that require special attention by providers working with TB patients.**

Answers on page 61.



## The Patient-Health Care Worker Relationship

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The patient-health care worker relationship is the basis for sharing information, communicating beliefs and feelings that affect care, and building trust between the patient and health care worker.

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A strong patient-health care worker relationship built on trust and the preservation of patient confidentiality will increase the likelihood that the patient will be compliant and adhere to therapy.

.....

### What is the Patient-Health Care Worker Relationship?

The **patient-health care worker relationship** is the basis for

- # Sharing information
- # Communicating beliefs and feelings that affect care
- # Building trust between the patient and health care worker

The quality of this relationship is important in determining whether medical treatment is successful — particularly in TB control, where long-term adherence to a treatment regimen is critical. A strong patient-health care worker relationship built on trust and the preservation of patient confidentiality will increase the likelihood that the patient will be compliant and adhere to therapy.



.....  
If either the health care worker or the patient fails to conform to the agreement, the relationship can break down. This may lead to misunderstandings, a lapse in communication, and treatment failure.  
.....

The patient-health care worker relationship can be viewed as an agreement between the patient and the health care worker. On the basis of the diagnosis, the health care worker recommends a given course of action and both parties (the patient and the health care worker) agree to work together to resolve the patient’s health problem. The agreement incorporates some basic rules that each party will observe during the course of the relationship; such rules include respecting each other’s rights and upholding certain responsibilities to each other and to other parties (such as the general public or the patient’s contacts). If either the health care worker or the patient fails to conform to this agreement, the relationship can break down. This may lead to misunderstandings, a lapse in communication, and treatment failure (see Module 9, Patient Adherence to Tuberculosis Treatment, for an example of an adherence agreement).

**Who is Considered a Health Care Worker?**

**Health care worker** refers to any member of a team of health professionals who care for and manage a TB patient, including

- # Physicians
- # Nurses
- # Outreach workers
- # Hospital discharge planners
- # Pharmacists
- # Social workers



.....  
For TB patients, the team of health care workers may include representatives from both the public and the private sectors.  
.....

For TB patients, the team of health care workers may include representatives from both the public and the private sectors. Because the health department has ultimate responsibility for the TB cases in its jurisdiction, the health department usually provides some oversight of the management of TB cases in the private sector.

Health care workers from the public sector who work with the private sector may find that health care workers from the private sector are reluctant to share patient information. Health care workers from the public sector must be prepared to inform health care workers from the private sector about health department confidentiality policies and procedures regarding the collection, management, and sharing of data gathered on TB patients.

.....  
A third party is a person or an organization not directly involved in the care of a patient's health problem.  
.....

**Who is Considered a Third Party?**

A **third party** is a person or an organization not directly involved in the care of a patient's health problem. Some third parties have legitimate reasons for becoming involved in the patient-health care worker relationship, such as

- # Providing financial reimbursements
- # Conducting research
- # Evaluating results of a program or intervention

However, this work is peripheral to the patient-health care worker interaction.

The difference between a health care worker and a third party is that health care workers have access to patient information and can share it among members of the health care worker team in order to care for the patient.



The only third parties who should have access to patient information are those whom the patient has specifically requested to be present during interviews or authorized to have access to records.

Trust is the key to a successful patient-health care worker relationship in which the rights and responsibilities of both the patient and the health care worker are upheld.

If a patient trusts or has confidence in his or her health care worker, he or she is more likely to be willing and able to adhere to a regimen and follow the health care worker's instructions and advice.

### Developing Trust

Trust is the key to a successful patient-health care worker relationship in which the rights and responsibilities of both the patient and the health care worker are upheld. Trust implies a firm reliance by the patient on the integrity, ability, and character of a health care worker. If a patient trusts or has confidence in his or her health care worker, he or she is more likely to be willing and able to adhere to a regimen and follow the health care worker's instructions and advice. Health care workers should strive to be worthy of this confidence by earning the patient's trust. Three ways to earn a patient's trust include

- # Respecting the patient's **autonomy**, the right of a patient to determine what will be done with his or her body, belongings, and personal information
- # Freely providing complete and accurate information
- # Rigorously maintaining confidentiality



.....  
It is extremely important that the health care worker safeguard all patient information, including the patient’s diagnosis, and assure the patient that this information will not be shared with authorities other than required by law.  
.....

.....  
If sensitive personal information is revealed to a third party without the patient’s permission, there may be serious consequences.  
.....

### **The Importance of Trust**

By bringing his or her health problem to the attention of a health care worker, the patient is entrusting personal and private information to the health care worker. As the health care worker interviews the patient, the patient may divulge information about lifestyle choices and risky, even illegal behaviors, such as injection drug use. In addition, some patients may reveal that they reside in the United States illegally and fear being reported to immigration authorities. It is extremely important that the health care worker safeguard all patient information, including the patient’s diagnosis, and assure the patient that this information will not be shared with authorities other than required by law.

If sensitive personal information is revealed to a third party without the patient’s permission, the patient’s trust of the health care worker could be threatened and may result in serious consequences:

- # The patient-health care worker relationship may be damaged, possibly affecting the care of the patient
- # The patient may be stigmatized or rejected by family, friends, and others
- # The patient may lose a job or be evicted from housing
- # The health care worker may lose the trust of other patients



**Study Questions 7.3-7.4**

- 7.3. What is the basis for the patient-health care worker relationship and why is it important in TB control?**
- 7.4. How is the patient-health care worker relationship like an agreement, and what are some of the consequences if either party fails to conform to the agreement?**
- 7.5. Who is considered a health care worker and who is the third party? What is the difference between the two?**

Answers on pages 62-63.



**Study Questions 7.6-7.7**

**7.6. Describe why trust is a key element in a successful patient-health care worker relationship and list three ways to develop trust.**

**7.7. What are some serious consequences of revealing sensitive personal information to a third party without the patient's permission?**

Answers on pages 63-64.





### Case Study 7.1

Van is a cook at a local restaurant. He came to the health department after his girlfriend, Tanya, told him that she had been diagnosed with TB disease. After undergoing tests for TB, it was confirmed that Van also has TB disease. Van is not from the United States and does not have the proper documents to be working in this country. During the contact investigation interview, Van was reluctant to provide information on where he worked. He did not want to get his employer in trouble and he does not want to be reported to immigration authorities. Van was also afraid that if people at work found out that he had TB that he would lose his job. Finally, Van also admitted to injecting drugs with some friends once in awhile, but was reluctant to give their names because he didn't want his friends to know that he had TB. He was also afraid his friends might be reported to the police.

# Why is it important to protect Van's confidentiality?

# What can the health care worker do to develop trust with Van?

Answers on pages 70-71.



## Protecting Patients’s Rights

### Patients’ Rights

Patients have certain rights concerning their personal and private information relevant to their medical care. Some of these rights are summarized in Table 7.1, page 23, and include the right to

- # Give or withhold authorization of disclosures
- # Maintain privacy
- # Have autonomy
- # Be given information

### The Right to Give or Withhold Authorization of Disclosures

**Disclosure** is the act of revealing or distributing personal information. A patient discloses his or her personal information to the health care worker in order to receive appropriate treatment and quality care. Health care workers working together to resolve a patient’s problem share information about that patient among themselves in order to provide quality care. In addition, health care workers are sometimes asked by a third party — an employer, a researcher, or even the press — to disclose patient information for specific purposes. The patient needs to give specific **authorization** or permission to allow a third party to have access to the patient’s confidential information. The third party’s request for patient information falls outside the bounds of the provider-health care worker relationship.

.....  
 Disclosure is the act of revealing or distributing personal information.

.....  
 The patient needs to give specific authorization or permission to allow a third party to have access to the patient’s confidential information.



To the extent possible, the patient should have control over

- # Who will receive any personal information
- # What information should be released to each requestor
- # The duration of the authorization

.....  
 Patient waivers are NOT needed for routine case reporting, the required reporting of suspected or confirmed TB cases to a public health authority, or when specific regulations allow the transfer of information needed to qualify a patient for government funding.

Often, patients are asked to sign a specific **waiver** or form, to allow their health information to be used by third parties. Figure 7.1 presents a sample authorization form for disclosure of medical record information. When such authorization forms are used, they should be carefully explained to patients so the patient’s consent to disclosure is informed. However, patient waivers are NOT needed for routine **case reporting**, the required reporting of suspected or confirmed TB cases to a public health authority, or when specific regulations allow the transfer of information needed to qualify a patient for government funding.

.....  
 The patient has a right to refuse requests by third parties or to limit the authorization in any way he or she wishes except where disclosure is provided by law.

The patient has a right to refuse requests for information by third parties, as well as the right to limit the authorization in any way he or she wishes except where disclosure is provided by law. TB programs and health care workers should carefully consider whether such requests are legitimate and valuable before asking patients to authorize disclosures.



### Authorization for Disclosure of Medical Record Information

Patient's name: \_\_\_\_\_ Date of birth: \_\_\_\_\_ Age: \_\_\_\_\_  
(Last, First, Middle Initial)

Address: \_\_\_\_\_ Home phone: \_\_\_\_\_  
(Street, Apartment No.)

\_\_\_\_\_ Work phone: \_\_\_\_\_  
(City, State, Zip Code)

The undersigned hereby authorizes and requests

\_\_\_\_\_

to provide

\_\_\_\_\_

(Health Care or Health Services Provider)  
(Identity of Third Party or Name of Any Duly Authorized Representative)  
with access to my medical records for the purposes of review and examination and further authorizes and requests that you provide such copies thereof as may be requested.

The foregoing is subject to such limitation as indicated below:

**G** 1. Confined to records regarding admission and treatment for the following medical condition or injury: \_\_\_\_\_  
on or about \_\_\_\_\_ at the following facility:  
(Date)  
\_\_\_\_\_

**G** 2. Covering records for the period from \_\_\_\_\_ to \_\_\_\_\_  
(Date) (Date)

**G** 3. Confined to the following specified information:  
\_\_\_\_\_  
\_\_\_\_\_

**G** 4. No limitations placed on dates, history of illness, or diagnostic and therapeutic information, including any treatment for alcohol and drug abuse. (*Signer to initial for authentication of this response*) \_\_\_\_\_

Expiration of this authorization, if any: \_\_\_\_\_  
(Date)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

*If signed by personal representative, state relationship and authority to do so.*

ANY DISCLOSURE OF MEDICAL RECORD INFORMATION BY THE RECIPIENT(S) IS PROHIBITED EXCEPT WHEN IMPLICIT IN THE PURPOSES OF THIS DISCLOSURE.

Figure 7.1 Example of an Authorization for Disclosure of Medical Record Information.  
Source: Guidelines on Institutional Policies for Disclosure of Medical Record Information, published by the American Hospital Association, copyright 1979.



.....  
Personal information shared  
by the patient with his or her  
health care worker is  
considered privileged  
information; that is,  
information that the health  
care worker has a  
responsibility to protect.  
.....

### The Right to Maintain Privacy

Health care workers should protect information revealed during provider-health care worker encounters, including all written or electronic records of these encounters. Only those persons directly involved in the care of the patient's health problem should have access to private information. Health care workers need to be aware of the patient's right to privacy in the collection, management, and sharing of data on TB patients. Personal information shared by the patient with his or her health care worker is considered **privileged information**; that is, information that the health care worker has a responsibility to protect. When the identity of the patient is either directly included in or can be deduced from such information, it is sometimes referred to as **patient-identifiable information**. This information is usually entered into the patient's medical record and into any secondary databases that are maintained by the health care worker or institution where the patient receives care. Secondary databases are usually maintained for the purposes of

- # Sharing information among members of the health care team
- # Conducting reporting and surveillance of diseases or medical conditions
- # Financing health care through reimbursements from the government or a private organization (such as an insurance company)
- # Conducting institutional review of the quality of care and appropriateness of expenditures



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Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent.

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Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions.

.....

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The provider-health care worker relationship is founded on the patient's consent to the care being provided.

.....

### The Right to Have Autonomy

Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent. The right to autonomy has some limitations designed to protect the patient (especially if the patient is a child or a mentally incompetent adult). In the case of such a patient, a parent or legal guardian acts as the decision maker. For example, the court may intervene if a parent or legal guardian withholds potentially life-saving treatment that is clearly indicated for a child.

Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions. This can happen in TB control when a patient with infectious or potentially infectious TB disease refuses treatment. Because he or she poses a significant health threat to other people, such a patient may receive a **court order**, which is an order issued by a court mandating DOT or, in very rare cases, detention in a facility until treatment is completed (see Module 9, Patient Adherence to Tuberculosis Treatment, for further information on nonadherence and its legal remedies).

With the exception of the circumstances mentioned above, autonomy means that health care workers should respect the decisions of patients about their health care. When a patient agrees to follow a treatment plan recommended by a health care worker, the patient is said to have given his or her consent to that plan. **Consent** is acceptance or approval of what is planned or done; it involves voluntary agreement to an action, whether it is a treatment option or a diagnostic test. The provider-health care worker relationship is founded on the patient's consent to the care being provided.



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Informed consent is a patient's written consent to a surgical or medical procedure or other course of treatment, given after the health care worker has informed the patient about the potential benefits, risks, and alternatives involved.

.....

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The patient has a right to be given information about his or her medical diagnosis, treatment regimen, and progress.

.....

**Informed consent** is a patient's written consent to a surgical or medical procedure or other course of treatment, given after the health care worker has informed the patient about the potential benefits, risks, and alternatives involved. The concept of informed consent is based on the principle that a health care worker has a duty to disclose information that allows the patient to make a reasonable decision regarding his or her own treatment. The informed consent procedure is provided for under state medical consent laws.

**The Right to Be Given Information**

The patient has a right to be given information about his or her medical diagnosis, treatment regimen, and progress. This allows the patient to make appropriate, informed decisions about his or her health care. For example, a patient with drug-resistant TB has a right to know the therapeutic options available, the duration of treatment, potential side effects of the drugs, and the expected outcome, or prognosis. This information may be valuable to the patient not only for making health care decisions, but also for making other decisions about important issues such as employment, housing, or family matters.



.....  
A patient also has a right to review the information in his or her medical record.  
.....

A patient also has a right to review the information in his or her medical record. A patient may want this information, to learn more about his or her health care or in preparation for a change of health care workers. If the record contains errors or omissions, the patient can request a correction or amendment. Usually, this request must be approved by the health care worker or institution that maintains the record. If the health care worker or institution does not agree that the record should be corrected or amended, the patient can usually file a **statement of disagreement** that indicates his or her version of the story. This is a statement filed by the patient stating there is a disagreement with the health care worker or institution regarding the patient's record. The documentation of a patient's medical history is very important and can have serious consequences for the patient; therefore, it is very important that it be as accurate and objective as possible.





**Table 7.1  
Summary of Patient Rights**

Type of Patient Right	Purpose
The right to give or withhold authorization of disclosures	The patient generally has the right to control who has access to confidential information except as otherwise provided by law. The patient needs to give specific authorization or permission to allow a third party to have access to confidential information.
The right to maintain privacy	Only those persons directly involved in the care of the patient's health problem should have access to private information. Health care workers should protect information revealed during provider-health care worker encounters, including all written or electronic records of these encounters.
The right to have autonomy	Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent. Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions.
The right to be given information	The patient has a right to information about his or her medical diagnosis, treatment regimen, and progress. This allows the patient to make appropriate, informed decisions about his or her health care.

.....  
 When interacting with patients, health care workers should always follow due process.  
 .....

**Following Due Process**

When interacting with patients, health care workers should always follow due process. **Due process** is an established course for governmental activities or procedures designed to safeguard the legal rights of the individual. It is extremely important that an established course be followed so that all patients are treated equally and receive attention for their individual needs.



Health care workers should receive training in and become informed about the policies and procedures used in their area for

- # Obtaining informed consent
- # Providing information to patients
- # Protecting confidentiality

.....  
 The use of standard protocols and forms can help ensure that important tasks are not omitted.  
 .....

The use of standard protocols and forms can help ensure that important tasks (such as obtaining informed consent or an authorization for release of information) are not omitted. Documentation is also a crucial part of due process. Health care workers should always document

- # Patient requests for information
- # Concerns about autonomy
- # Decisions about disclosure of patient information



**Study Questions 7.8-7.10**

**7.8. What is an authorization or waiver form and when is it used?**

**7.9. What is patient-identifiable information? List four specific uses for this information.**

**7.10. What is informed consent?**

Answers on pages 64-65.



**Study Questions 7.11-7.12**

**7.11. What are the four types of patient rights and what is the purpose of each of the patient rights?**

**7.12. What is due process and why is it important?**

Answers on page 65.



### Case Study 7.2

**Mr. Alvin Jones is a patient with infectious TB disease who has been recently discharged from the hospital. While hospitalized, Mr. Jones was very sick and had no problems with taking his medication or undergoing diagnostic procedures. Now that he is back at home, he has stopped taking his medications, has missed two clinic appointments, and has continually refused to speak to the health care worker assigned to his case. After many attempts to inform Mr. Jones of his condition and the need for treatment, the health department finally obtained a court order requiring Mr. Jones to complete a directly observed therapy regimen. Mr. Jones, not wanting to get into legal problems, has reluctantly agreed to meet with the health care worker to establish a treatment plan.**

**# Why is the health department able to obtain a court order, despite Mr. Jones' wish to stop treatment?**

**# What should be done to protect Mr. Jones' rights to autonomy, information, and privacy?**

Answers on pages 71-72.



## TB Control and Confidentiality

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The three primary goals of TB prevention and control are to identify and treat TB disease; to identify and evaluate exposed contacts; and to test populations at high risk for TB, and provide treatment of LTBI as indicated.  
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State and local health departments have the primary responsibility for preventing and controlling TB.  
.....

### Goals of TB Prevention and Control

The three primary goals of TB prevention and control are to

- # Identify and treat persons who have active TB disease
- # Identify and evaluate exposed contacts, offering appropriate treatment as indicated
- # Test populations at high risk for TB infection and disease in order to detect infected persons, and provide treatment of latent TB infection (LTBI) to prevent progression to active TB

State and local health departments have the primary responsibility for preventing and controlling TB. To meet this challenge successfully, TB control programs should be able to carry out the following core components:

- # Identifying TB cases
- # Ensuring adequate therapy
- # Identifying high-priority candidates for treatment of LTBI
- # Collecting and analyzing data
- # Conducting overall planning and policy development
- # Providing laboratory and diagnostic services
- # Providing training and education



Health care workers need to be aware of the confidentiality issues that are relevant to patient-health care worker encounters as well as to the collection, management, and sharing of data on TB patients.

The following section highlights how confidentiality is an essential issue in several of the core components of a TB control program. Health care workers need to be aware of the confidentiality issues that are relevant to patient-health care worker encounters as well as to the collection, management, and sharing of data on TB patients.

**Confidentiality in Identifying and Managing TB Cases**

Most persons who have TB disease are diagnosed when they seek medical care for symptoms caused by TB or other medical conditions. Reports of suspected or confirmed TB cases are required to be submitted to public health authorities (see Module 8, Tuberculosis Surveillance and Case Management in Hospitals and Institutions).

Because TB is considered a significant threat to the public's health, the disclosure of the patient information from the health care worker to a public health authority is allowed for the purpose of TB control.

Cases of TB are reported to federal, state, or local health authorities based upon laws governing the locality. Because TB is considered a significant threat to the public's health, the disclosure of the patient information from the health care worker to a designated public health authority is allowed for the purpose of TB control. In addition to routine case reporting, some TB control programs conduct active surveillance to identify TB cases through laboratory or pharmacy records. Health departments are required to protect the confidentiality of all TB case reports.

Once the information about a suspected or confirmed TB case is transmitted to or obtained by the health department, health care workers use this information to ensure that the necessary steps are taken to treat the patient and halt the spread of disease.



When a TB case report has been submitted, the health care worker should check the TB program database to see if the case has been reported previously. If so, he or she should obtain information about the patient's past clinic visits, chest x-ray reports, adherence history, bacteriology and susceptibility results, and medication history, including the administration of directly observed therapy (DOT). It is crucial that this information be given immediately to the health care worker managing the case to ensure appropriate medical treatment. As confidentiality laws permit, this information may also be shared with others providing direct care to the patient.

. . . . .  
If a patient travels or moves from one health jurisdiction to another, the health department of the patient's home jurisdiction should notify the health department for the area to which the patient is moving.  
. . . . .

If a patient travels or moves from one health jurisdiction to another, the health department of the patient's home jurisdiction should notify the health department for the area to which the patient is moving. It is important that as much information as possible be relayed to the receiving jurisdiction, within the limitations of current laws and regulations governing the confidentiality of records. Health care workers should be aware that legal obligations of confidentiality may vary widely from state to state (see Module 8, Tuberculosis Surveillance and Case Management in Hospitals and Institutions).





.....  
Health care workers should never fax patient information if they are not sure if the receiving fax machine is in a secure area.  
.....

Although sharing necessary information between health care workers, health departments, and health jurisdictions is encouraged to protect the health of the patient and the public, information should be shared only on a need-to-know basis. In addition, when sending or faxing information, measures should be taken to ensure confidentiality. For example, any materials sent through the mail should be sent by way of secure mail to the care of a specific person. Health care workers should never fax patient information if they are not sure if the receiving fax machine is in a secure area. Furthermore, all information sent by fax should be sent to a specific person and should be labeled confidential.

Contact investigations and targeted screening for TB are additional ways to identify TB cases. Both these activities require the health care worker to practice confidentiality (see Confidentiality and Identifying High-Priority Candidates for Treatment for Latent TB Infection, page 34).

### **Confidentiality and Ensuring Adequate Therapy**

When a suspected or confirmed TB case has been identified, a treatment plan is made for the patient and the patient’s informed consent is obtained (see Module 4, Treatment of Tuberculosis Infection and Disease). The treatment plan usually includes information on

- # The prescribed regimen
- # Monitoring for adverse reactions and response to treatment
- # Ensuring adherence to the regimen, which may involve giving directly observed therapy and various incentives and enablers



.....  
It should be made clear from the beginning of treatment that confidentiality of the patient’s personal information is an important priority.  
.....

It should be made clear from the beginning of treatment that confidentiality of the patient’s personal information is an important priority. Health care workers should discuss confidentiality with the patient and determine who, if anyone, will be allowed to know about the patient’s care or to participate in decision-making. A trusted family member or close friend can be very valuable in supporting the patient during his or her care; however, in no case should such a person be “recruited” to assist without the patient’s request and prior knowledge.

.....  
DOT is offered by health department staff to ensure that the patient receives adequate therapy and completes a recommended regimen.  
.....

In some cases, the plan for ensuring adherence to the regimen may involve self-administered therapy with occasional visits to the health care worker for monitoring. More often, however, directly observed therapy (DOT) is offered by health department staff to ensure that the patient receives adequate therapy and completes a recommended regimen. DOT involves frequent encounters between the patient and the health care worker, which may take place at sites in the community (for example, the patient’s home, work-place, or other locations). Health care workers should make sure that the patient’s confidentiality is protected during these encounters. This means that

- # The location chosen should allow private conversations
- # No other persons should be present without the patient’s permission
- # Any documents or materials brought to such encounters should be protected from access by unauthorized persons



.....  
A TB patient may decide not to cooperate with the health care worker in completing an adequate regimen. When this happens, the health care worker has a responsibility to review the causes of the patient's nonadherence, identify potential solutions, and try to meet the patient's needs to the extent possible.  
.....

Occasionally, a TB patient may decide not to cooperate with the health care worker in completing an adequate regimen. When this happens, the health care worker has a responsibility to

- # Review the causes of the patient's nonadherence
- # Identify potential solutions
- # Try to meet the patient's needs to the extent possible to facilitate completion of therapy

If these measures fail, the patient may be required to continue treatment under a court order or even be confined for the duration of treatment. Because the threat to the public's health is serious, an uncooperative TB patient can be quarantined until noninfectious or, in some jurisdictions, committed to a treatment facility. This is a very rare event, which is fortunate because it involves a serious breach of the patient's right to autonomy.

.....  
Any health department or law enforcement officials who become involved in enforcing such orders should take great care to protect the patient's right to privacy.  
.....

In such a situation, maintaining the confidentiality of patient information is critical. Although disclosure of patient information is necessary to obtain a court order or an order for confinement, such disclosure should be strictly limited to the appropriate government authorities who need the information. Any health department or law enforcement officials who become involved in enforcing such orders should take great care to protect the patient's right to privacy. A breach of confidentiality in these circumstances can further undermine the patient-health care worker relationship and lead to continued resistance to adherence-promoting measures.



.....  
When a reported case of TB is potentially infectious, a contact investigation is conducted to identify persons who may have TB disease, as well as those who are newly infected with *M. tuberculosis*.  
.....

**Confidentiality and Identifying High-Priority Candidates for Treatment for Latent TB Infection (LTBI)**

When a reported case of TB is potentially infectious, a contact investigation is conducted to identify persons who may have TB disease, as well as those who are newly infected with *M. tuberculosis*. These newly infected persons are high-priority candidates for treatment for LTBI.

When a contact investigation is to be conducted for a reported TB patient, a health care worker should

- # Interview the patient
- # Explain the goals of the investigation
- # Explain why it is important to know the names of contacts
- # Tell the patient about his or her right to privacy
- # Explain the measures that will be taken to maintain confidentiality

.....  
Patient interviews should take place under conditions that are private and maintain confidentiality.  
.....

**Contact Investigations and Confidentiality.** Contact investigations pose some unique challenges to maintaining patient confidentiality. Whenever possible, the health care worker should ensure that patient interviews take place under conditions that are private and maintain confidentiality. The patient should be told about his or her rights to privacy and reassured of the measures that will be taken to maintain confidentiality.



.....  
The health care worker should be sensitive to the patient's fears, explain the importance of screening the contacts, and assure the patient that all information, including the patient's name, will be kept confidential.  
.....

The health care worker should be aware that some patients may be reluctant to identify some or all of their contacts. For example, a patient may not want to identify people who use illegal drugs with him or her, or the patient simply may not want his or her friends to know that he or she has TB. In addition, if the patient has contacts who are in the country illegally, the patient may be reluctant to identify contacts for fear they will be reported to immigration authorities. The health care worker should

- # Be sensitive to the patient's fears
- # Explain the importance of screening the contacts
- # Assure the patient that all information, including the patient's name, will be kept confidential and will not be shared with authorities

.....  
Patients should be assured that the contacts they named will not be told who identified them as a contact.  
.....

The health care worker and the patient should decide who will notify the contacts and make appointments for them to receive TB testing at the health department. Some TB patients prefer to notify their contacts themselves, especially when the contacts are family members or close friends. Others prefer that the health worker notify the contacts to protect their privacy; in this instance, the patient should be assured that the **contacts they name will not be told who identified them as a contact.**



.....  
The health care worker should be careful not to inadvertently reveal clues about the TB patient (index case) during contact follow-up.  
.....

Health care workers should conduct contact investigations without jeopardizing the TB patient's confidentiality. The health care worker should be careful not to inadvertently reveal clues about the TB patient (index case) during contact follow-up. Health care workers can use the following strategies to protect the confidentiality of the patient when conducting a contact follow-up during contact investigations:

- # Gender-neutral language should be used (even if it requires using bad grammar). For example, "Somebody was diagnosed with TB and they were [or "that person was"] concerned about you" instead of "A woman was diagnosed with TB and she was concerned about you."
- # The index case's health care worker, place and dates of diagnosis, or hospitalization should not be mentioned
- # The environment in which the exposure occurred should not be mentioned. For example, "You have been around somebody who has TB" instead of "You have been around somebody at work who has TB."
- # The dates of exposure should not be specified
- # When following-up on interjurisdictional referrals, the county or state that initiated the referral should not be mentioned
- # Confidentiality should not be violated even if contacts refuse to be evaluated until they have been told the index patient's identity



In addition, HIV/AIDS programs conduct **partner notification** to identify and counsel the sexual and needle-sharing contacts of HIV-infected persons; this notification is confidential and depends on the voluntary cooperation of the patient. When an HIV-infected person is diagnosed with TB disease, health care workers should explain what a contact is for the purpose of TB investigations and assure the patient that his or her name and HIV status will be kept confidential.

.....

In a situation where an outbreak of TB has occurred or when a contact investigation is conducted in a worksite or institutional setting in which numerous contacts may have been infected, it becomes difficult to maintain confidentiality.

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To prevent breaches in confidentiality, patients should be counseled to inform only persons they trust about their diagnosis and ask these persons to safeguard that information.

.....

In a situation where an outbreak of TB has occurred or when a contact investigation is conducted in a work site or institutional setting in which numerous contacts may have been infected, maintaining confidentiality is challenging. Sometimes, a contact guesses the identity of the source case and it becomes difficult to contain rumors. In addition, a friend, family member, or co-worker of the patient may divulge information about the patient to others. Patients should be counseled that despite the health care worker's best efforts, sometimes confidentiality is not preserved. The patient and the health care worker should discuss this possibility and be prepared to address this issue in the event that patient confidentiality is not maintained. To prevent breaches in confidentiality, patients should be counseled to inform only persons they trust about their diagnosis and to ask these persons to safeguard that information.



.....  
It should not be obvious to other residents or patients that a person is being evaluated because of a positive skin-test reaction.  
.....

**Testing and Confidentiality.** Testing for TB infection may be mandatory for specific groups of people. In health-care facilities or other institutional settings (for example, homeless shelters, correctional facilities, drug-treatment centers, AIDS clinics or hospices, homes for the mentally ill), residents and employees may be required to participate in an ongoing tuberculin skin-testing program. In such situations, testing procedures should be designed and records maintained in such a way that confidentiality is protected. It should not be obvious to other residents or patients that a person is being evaluated because of a positive skin-test reaction.

Confidentiality measures are not only important in testing high-priority candidates for LTBI, but are also relevant in providing and monitoring treatment for LTBI. Treatment for LTBI should be offered to persons with a positive skin-test reaction or a high likelihood of infection with *M. tuberculosis* according to current guidelines and recommendations.

### **Confidentiality and Conducting Other Core Activities**

In addition to identifying TB cases, ensuring adequate therapy, and identifying high-priority candidates for treatment for LTBI, TB programs are responsible for

- # Collecting and analyzing data
- # Conducting overall planning and policy development
- # Providing laboratory and diagnostic services
- # Providing training and education





.....  
Confidentiality is important  
when collecting and  
analyzing data with patient-  
identifiable information.

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.....  
Policies and procedures  
should be in place to protect  
all TB reports, records, and  
files containing patient names  
or other identifying  
information.

.....

Confidentiality is important in several of these core activities, including collecting and analyzing data with patient-identifiable information. TB control programs develop specific policies to ensure the security and confidentiality of TB records and should train staff members in procedures for maintaining and carrying out these policies. Policies and procedures should be in place to protect all TB reports, records, and files containing patient names or other identifying information. An example of a form used for the protection of persons with reported cases of TB, used at the federal level, is included in Figure 7.2.



**Assurance of Confidentiality for  
Reports of Verified Cases of Tuberculosis (RVCT)  
Centers for Disease Control and Prevention (CDC)  
Control Number M3-91-027**

Reports of Verified Cases of TB (RVCT) are submitted to the CDC from TB control programs in all states, most large cities, and U.S. territories and commonwealths. The surveillance information requested by CDC consists of detailed reports of persons with TB, including information on the individual's HIV serostatus, demographics (e.g., homelessness, residence in a correctional institution, or residence in a long-term care facility), alcohol and drug use, drug therapy, and drug susceptibility results. The data are used by U.S. Public Health Service scientists and cooperating state and local health officials to help understand and control the spread of TB.

Information that would permit identification of any individual on whom a record is maintained by CDC is collected with a guarantee to the agency, institution, physician, or individual providing the information that it will be held in strict confidence, will be used only for purposes stated in this assurance, and will not otherwise be disclosed or released without the consent of the individual in accordance with Sections 306 and 308(d) of the Public Health Service Act (42 U.S.C. 242k and 242m[d]). Data or information retained by the state or local health officials or by authorized collaborating researchers will be protected in accordance with state law.

Information reported to CDC will be used without identifiers for statistical and analytic summaries in which no individual on whom a record is maintained can be identified and for special studies of the transmission, natural history, and epidemiology of TB associated with HIV infection. When necessary for confirming information, or in the interest of public health and disease prevention, CDC may confirm information contained in case reports or may notify other medical personnel or health officials of such information. In each instance, only the information necessary will be disclosed.

Collaborative research efforts with an important public health purpose will require approval by the Director of CDC pursuant to strict conditions. If disclosure of identifying information to the collaborating researchers is essential to conduct the research, a written certificate will be required that identifying information obtained from the CDC will be managed as confidential and will not be released or re-disclosed. No information that could be used to identify any individual on whom a record is maintained, whether directly or indirectly, will be made available to anyone for non-public health purposes. In particular, such information will not be disclosed to the public; parties involved in civil, criminal, or administrative litigation; or non-health agencies of the federal, state, or local government.

*Figure 7.2 Protection of Patient-Identifiable Information by the CDC.*



Local policies regarding the security and confidentiality of such information, especially HIV test results, must adhere to all laws applicable in state and local jurisdictions.

.....

Any surveillance information sent through the mail should be stamped "confidential," addressed to a specific person (or sent to that person's attention), and sent by secure mail.

.....

For clinical care purposes, HIV-related information should be shared between TB health care workers and other health care workers in accordance with state and local laws.

.....

Local policies regarding the security and confidentiality of such information, especially HIV test results, must adhere to all laws applicable in state and local jurisdictions. These protections should include the use of TB surveillance databases such as CDC's Tuberculosis Information Management System (TIMS). These databases are encrypted to protect information during transfers of data for reporting purposes. Although such databases allow for the collection and storage of personal identifiers such as names and street addresses for local and state TB surveillance purposes, these identifiers are not transmitted to CDC. In general, any surveillance information sent through the mail should be stamped "confidential," addressed to a specific person (or sent to that person's attention), and sent by secure mail. These precautions will help to limit unauthorized access to surveillance information.

Because HIV infection and AIDS can have serious implications for TB control, some health jurisdictions have specific rules and regulations for the sharing of information between TB and HIV/AIDS programs. AIDS is a reportable disease in every state. The requirements for reporting HIV infection differ from state to state, and health care workers should be familiar with local reporting requirements. HIV reports are held in strictest confidence and in many jurisdictions are protected by statute from subpoena. For clinical care purposes, HIV-related information should be shared between TB health care workers and other health care workers in accordance with state and local laws.



.....  
Sharing information on HIV serostatus with persons outside the HIV/AIDS and TB surveillance programs of the same health department should only be done with the informed consent of the patient.  
.....

The sharing of surveillance information between HIV/AIDS programs and TB programs within the same health department is necessary to conduct both TB and HIV/AIDS surveillance programs and to allow for adequate investigation of TB and HIV/AIDS cases. In general, TB surveillance programs and staff should adhere to the same confidentiality standards as HIV/AIDS surveillance programs and should work with local HIV/AIDS programs to establish equivalent data confidentiality systems. Sharing information on HIV serostatus with persons outside the HIV/AIDS and TB surveillance programs of the same health department should only be done with the informed consent of the patient.

Program evaluation reports serve as a basis for policy development and are often shared with appropriate public, private, and community groups. TB programs collect and analyze

- # Morbidity rates
- # Trends
- # Demographic characteristics of the TB patient population in the area

They also assess program performance by determining the rates for

- # Completion of therapy
- # Contact identification
- # Initiation and completion of treatment for LTBI

.....  
Program evaluation reports should never include patient-identifiable information.  
.....

Program evaluation reports should **never** include patient-identifiable information, such as names, addresses, or even detailed demographic information if such information allows the determination of a patient's identity.



**Study Questions 7.13-7.15**

**7.13. Why is disclosure of patient information allowed for case reporting that is required by law?**

**7.14. How should health care workers protect confidentiality during DOT encounters?**

**7.15. What information should the health care worker explain to a patient regarding the protection of confidentiality during a contact investigation?**

Answers on pages 66-67.



**Study Questions 7.16-7.17**

- 7.16. What are some strategies that a health care worker can use to protect the TB case's (index case's) identity when conducting a contact follow-up during contact investigations?**
- 7.17. Explain how other program activities, especially those involving data collection and analysis, require adequate measures to provide data security and protect confidentiality.**

Answers on pages 67-68.



### Case Study 7.3

**Ms. Rita Ramirez, a young mother of two children, has been diagnosed with infectious TB. She is also infected with HIV, which she contracted through sexual contact with her current partner, an HIV-infected injection drug user. Ms. Ramirez works in a factory that assembles small parts for electronic appliances; there are over 250 workers at the plant. She is very concerned about her job security, having only recently begun work on a temporary basis. Ms. Ramirez has consented to a treatment plan including a DOT regimen and is willing to cooperate with the contact investigation. She will inform her household contacts, but does not want anyone at work to know she has TB disease.**

**# Why is it important to protect the confidentiality of Ms. Ramirez' information?**

**# What steps should be taken to ensure that confidentiality is maintained?**

Answers on pages 72-73.



## Measures to Protect Patient Confidentiality

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.....  
Health care workers can  
provide measures to protect  
confidentiality anywhere.  
.....

### Protecting Patient Confidentiality

Health care workers can provide measures to protect confidentiality anywhere, whether in an office, clinic, institution, or in the field.

**Any situation.** In any situation there are important measures that all health care workers can take to protect patient confidentiality:

- # Confirm the patient's identity at the first encounter
- # Never discuss the patient's case with anyone without the patient's permission (including family and friends during off-duty hours)
- # Never leave hard copies of forms or records where unauthorized persons may access them
- # Use only secure routes to send patient information (for example, official mail) and always mark this information confidential
- # When using an interpreter, ensure that the interpreter understands the importance of patient confidentiality





.....  
Great care should be taken to protect patient confidentiality in health care settings and in the field.

.....  
Patient encounters should always take place in private rooms or areas.

**When in an office, clinic, or institution.** Great care should be taken to protect patient confidentiality in health care settings and in the field.

# Conduct patient interviews in private rooms or areas (Figure 7.3)

# Never discuss cases or use patients' names in a public area

# If a staff member or health care worker requests patient information, establish his or her authority to do so before disclosing anything

Confidentiality can be further protected in the ongoing management of data collected on the TB patient.

# Keep records that contain patient names and other identifying information in closed, locked files (Figure 7.4)

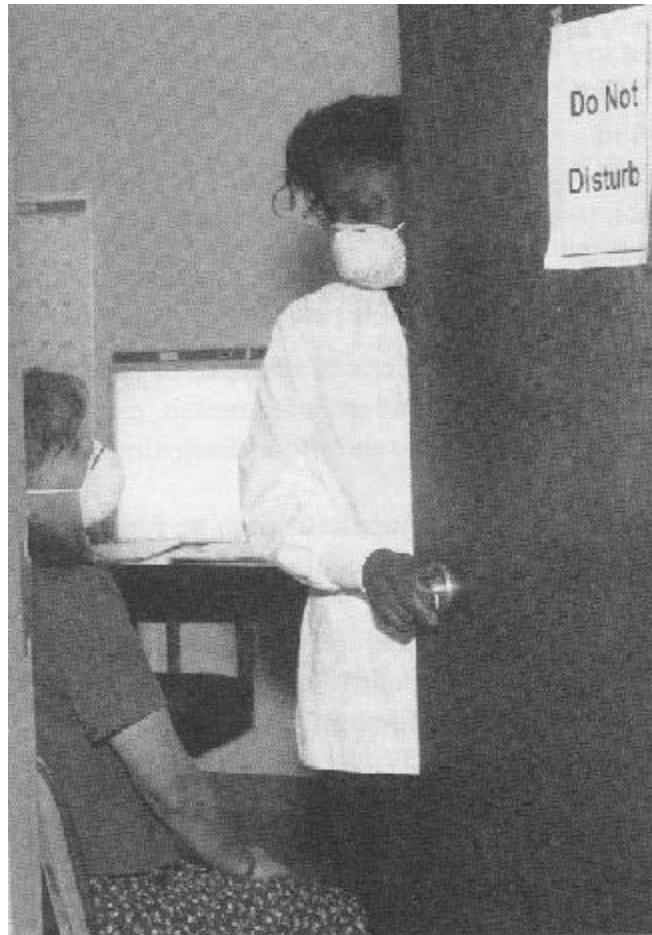
# Restrict access to electronic databases to designated staff

# Carefully protect computer passwords or keys; never give them to unauthorized persons

# Carefully safeguard computer screens

# Keep computers in a locked or restricted area; physically or electronically lock the hard disk

# Keep printouts of electronic information in a restricted or locked area; printouts that are no longer needed should be destroyed



*Figure 7.3 Conducting patient interviews in privacy.*



Figure 7.4 Closed, locked files.

.....  
Health care workers have a responsibility to protect patient records from unauthorized access.  
.....

Health care workers have a responsibility to protect patient records from unauthorized access. Information that should be kept in closed, locked files except when being processed by authorized staff include

- # All medical records
- # Report of Verified Case of TB (RVCT) forms
- # Communicable disease report cards
- # Other records that contain patient names and other identifying information



.....  
Access to all RVCT forms, communicable disease report cards, and the files containing them should be restricted to designated TB program staff who are directly involved with surveillance or case work and who have a need to know.

.....  
.....  
Electronic surveillance databases should be restricted to designated TB surveillance staff who are directly involved with surveillance and other case work and who have a need to know.

.....  
.....  
All hard copy output (for example, file listings or reports) generated by surveillance databases must be kept in a restricted or locked area.

Offices should be locked during nonbusiness hours. No papers should be exposed when workers are away from the work area, even for brief periods. Access to all RVCT forms, communicable disease report cards, and the files containing them should be restricted to designated TB program staff who are directly involved with surveillance or case work and who have a need to know.

Electronic surveillance databases should be restricted to designated TB surveillance staff who are directly involved with surveillance and other case work, and who have a need to know. Access to such databases should be protected by a combination of user IDs and passwords; user IDs should be issued only to staff who require access to the database to perform their official duties. Passwords should be changed on a regular basis and should not be easy to deduce (for example, employee's names, birthdates, or other personal information should not be used as passwords).

All computers and work stations accessing surveillance databases should be kept in a locked or restricted area. If this is not feasible, the hard disk must be physically or electronically locked when the computer is not in use. All hard copy output (for example, file listings or reports) generated by surveillance databases must be kept in a restricted or locked area. All hard copy output that is no longer needed must be destroyed.



. . . . .  
When a disclosure occurs during the course of a field investigation, it is a good idea to document what information was given out and to whom, in case there are any follow-up questions from the patient or the person who was informed of the patient's health problem.  
. . . . .

**When in the field.** In the course of locating a patient for DOT or conducting a contact investigation in the field, TB workers may need to ask for patients by name or inquire about a patient's work location and habits. This should be done as discreetly as possible. Before giving out patient information to anyone, health care workers should ask themselves, "Does this person need to know?" Health care workers do need to identify themselves as having a legitimate reason to seek a particular individual, but there is no need to disclose the nature of the problem or any specific details of the case in question. When a disclosure occurs during the course of a field investigation, it is a good idea to document what information was given out and to whom it was given, in case there are any follow-up questions from the patient or the person who was informed of the patient's health problem.



.....  
In the patient's home, health care workers should allow the patient to determine who is present during an interview.  
.....

In the patient's home, health care workers should allow the patient to determine who is present during an interview. Family members or friends should be present and participate in the discussion only if the patient specifically requests this. In the field there are important measures that can be taken to protect patient confidentiality:

- # Be discreet when making patient visits
- # Conduct patient interviews in private; never discuss the case in a public place
- # Don't leave sensitive or confidential information in messages for the patient on a door; but if a message must be left on the door, it should be left in a sealed envelope, marked confidential, and addressed to a specific person
- # Don't leave sensitive or confidential information on an answering machine that other people can access
- # Don't leave sensitive or confidential information with a neighbor or friend, and be careful not to disclose the patient's condition when gathering information on his or her whereabouts

Table 7.2 summarizes the important measures all health care workers can take to protect patient confidentiality.



**Table 7.2**  
**Measures to Protect Patient Confidentiality**

<p><b>Any situation</b></p> <ul style="list-style-type: none"><li># Confirm the patient's identity at the first encounter</li><li># Never discuss the patient's case with anyone without the patient's permission (including family and friends during off-duty hours)</li><li># Never leave hard copies of forms or records where unauthorized persons may access them</li><li># Use only secure routes to send patient information (for example, official mail) and always mark this information confidential</li><li># When using an interpreter, ensure that the interpreter understands the importance of patient confidentiality</li></ul>
<p><b>When in an office, clinic, or institution</b></p> <ul style="list-style-type: none"><li># Conduct patient interviews in private rooms or areas</li><li># Never discuss cases or use patients' names in a public area</li><li># If a staff member or health care worker requests patient information, establish his or her authority to do so before disclosing anything</li><li># Keep records that contain patient names and other identifying information in closed, locked files</li><li># Restrict access to electronic databases to designated staff</li><li># Carefully protect computer passwords or keys; never give them to unauthorized persons</li><li># Carefully safeguard computer screens</li><li># Keep computers in a locked or restricted area; physically or electronically lock the hard disk</li><li># Keep printouts of electronic information in a restricted or locked area; printouts that are no longer needed should be destroyed</li></ul>
<p><b>When in the field</b></p> <ul style="list-style-type: none"><li># Be discreet when making patient visits</li><li># Conduct patient interviews in private; never discuss the case in a public place</li><li># Don't leave sensitive or confidential information in messages for the patient on a door; but if a message must be left on the door, it should be left in a sealed envelope, marked confidential, and addressed to a specific person</li><li># Don't leave sensitive or confidential information on an answering machine that other people can access</li><li># Don't leave sensitive or confidential information with a neighbor or friend, and be careful not to disclose the patient's condition when gathering information on his or her whereabouts</li></ul>



**Study Question 7.18**

**7.18 List the ways in which a patient's confidentiality can be protected in**

**# Any situation**

**# An office, clinic, or institution**

**# The field**

Answers on pages 68-69.





### Case Study 7.4

**Rolando is a health care worker at a busy TB clinic. It is the end of a very busy Friday afternoon. He is trying to wrap things up and go home after his extremely stressful week. He is going through the patient-related papers and forms he has been working on that day. He is on his way to put the papers and forms in the file cabinet when he is interrupted by a phone call from his babysitter. His babysitter explains that she has to leave early that day. Thinking it is an emergency, Rolando hastily hands over the files to his co-worker Sam in the clinic area. He asks Sam to put the files on his desk. Before getting a reply from Sam, he leaves. Sam was not very happy because he was just leaving himself. He ends up leaving the files on the table in the clinic, an area where other TB patients may see the files.**

**# What measures should Rolando have taken to protect patient confidentiality?**

Answers on pages 73-74.



### Case Study 7.5

Another outreach worker, Janice, has been trying to contact her patient Jerry for several days. She has visited his home several times, and tried to call him on the telephone. One time when she visits Jerry's house she sees Jerry's neighbor. The neighbor tells Janice that Jerry just left. Janice introduces herself to Jerry's neighbor and explains that she is from the TB clinic in the health department and is looking for Jerry. She tells the neighbor that the reason she is looking for Jerry is that he has TB and has missed taking treatment for over 1 week. She also tells the neighbor that if she sees Jerry to please tell him that she has stopped by to see him. Finally, she leaves a message for Jerry on the door of his apartment. She does not have any envelopes for her letter, but decides Jerry must really get her message and so she tapes it to his front door.

# Did Janice do anything that possibly threatens Jerry's confidentiality? What measures should she have taken to protect patient confidentiality?

Answers on page 74.



## SUMMARY

The protection of private information is commonly referred to as confidentiality. Confidentiality involves the protection of information revealed during patient-health care worker encounters, including all written or electronic records of these encounters. Confidentiality is an essential issue in many different aspects of TB control. Health care workers need to be aware of the confidentiality issues that are relevant to patient-health care worker encounters as well as to the collection, management, and sharing of data gathered on TB patients. Health care workers have a responsibility to protect patients' confidentiality. However, health care workers may have to override these rights in some cases, in the interest of protecting the public's health. For example, patients with infectious TB disease may have some rights curtailed until they are no longer infectious.

The patient-health care worker relationship relies on an agreement to continue treatment until the patient's health problem is resolved. Health care workers should respect the patient's autonomy, freely provide complete and accurate information, and rigorously maintain confidentiality. The patient-health care worker relationship is the basis for sharing information, communicating beliefs and feelings that affect care, and building trust in the value of the interaction. The patient-health care worker relationship can be viewed as an agreement between the patient and the health care worker. Basic rules that each party will observe include respecting each other's rights and upholding certain responsibilities. If either the health care worker or the patient fails to conform to this agreement, the relationship can break down and lead to misunderstandings, a lapse in communication, or even treatment failure.

The term health care worker refers to any member of a team of health professionals who care for and manage a TB patient, including physicians, nurses, outreach workers, hospital discharge planners, pharmacists, and social workers. A third party is a person or organization not directly involved in the care of a patient's health problem. This term includes anyone who does not play an integral part in the patient-health care worker relationship.

Trust is the key to a successful patient-health care worker relationship in which the rights and responsibilities of both patient and health care worker are upheld. Trust implies a firm reliance by the patient on the integrity, ability, and character of a health care worker. If a patient trusts or has confidence in his or her health care worker, he or she is more likely to be willing and able to adhere to a regimen and follow the health care worker's instructions and advice. Health care workers should strive to be worthy of this confidence by earning the patient's trust.



Patients have rights concerning their personal and private information relevant to their medical care. These rights are summarized in the table below.

<b>Type of Patient Right</b>	<b>Purpose</b>
The right to give or withhold authorization of disclosures	The patient generally has the right to control who has access to confidential information except as otherwise provided by law. The patient needs to give specific authorization or permission to allow a third party to have access to confidential information.
The right to maintain privacy	Only those persons directly involved in the care of the patient's health problem should have access to private information. Health care workers should protect information revealed during provider-health care worker encounters, including all written or electronic records of these encounters.
The right to have autonomy	Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent. Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions.
The right to be given information	The patient has a right to information about his or her medical diagnosis, treatment regimen, and progress. This allows the patient to make appropriate, informed decisions about his or her health care.

When interacting with patients, the health care workers should always follow due process. Due process is an established course for governmental activities or procedures designed to safeguard the legal rights of the individual. The use of standard protocols and forms can help ensure that important tasks (such as obtaining informed consent or an authorization for release of information) are not omitted. Documentation is also a crucial part of due process.

Confidentiality is an essential issue in several of the core components of a TB control program. Health care workers are required to conduct routine case reporting, which is reporting cases of suspected or confirmed TB cases to a public health authority that collects and analyzes the information. Because TB is considered a significant threat to the public's health, the disclosure of patient information is allowed for the purpose of TB control. Health departments are required to protect the confidentiality of such case reports. If a patient travels or moves, the health department of the patient's home jurisdiction should notify the health department for the area to which the patient moves. It is important that as much information as possible is relayed to the



receiving jurisdiction, within the limitations of current laws and regulations governing the confidentiality of records.

When a suspected or confirmed TB case has been identified, a treatment plan is made for the patient and the patient's informed consent is obtained. It should be made clear from the beginning of treatment that confidentiality of the patient's personal information is an important priority. Health care workers should discuss confidentiality with the patient and determine who, if anyone, the patient wishes to know about his or her care or to participate in decision-making.

When a contact or source investigation is to be conducted for a reported TB case, a health care worker should interview the patient, explaining the goals of the investigation, and why it is important to know the names of contacts. The patient should be told about his or her right to privacy and the measures that will be taken to maintain confidentiality. Health care workers should conduct contact investigations without jeopardizing the TB patient's confidentiality. The patient should be assured that the contacts they name will not be told who identified them as a contact. The health care worker should be careful not to inadvertently reveal clues about the TB patient (index case) during contact follow-up.

Testing for TB infection may be mandatory for specific groups of people. Testing procedures should be designed and records maintained in such a way that confidentiality is protected. It should not be obvious to other residents or patients that a person is being evaluated because of a positive skin-test reaction.

TB programs are responsible for collecting and analyzing data, conducting overall planning and policy development, providing laboratory and diagnostic services, and providing training and education. TB control programs develop specific policies to ensure the security and confidentiality of TB records and should train staff members in procedures for maintaining and carrying out these policies. It is particularly important to protect information on HIV serostatus: in general, TB program staff should adhere to the same confidentiality standards as HIV/AIDS surveillance programs and should work with local HIV/AIDS programs to establish equivalent data confidentiality systems.

Health care workers can provide measures to protect confidentiality anywhere, whether in an office, clinic, institution, or in the field.



## Additional Reading

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## ANSWERS TO STUDY QUESTIONS

### 7.1. What is confidentiality and why is it important in TB control? (pages 5-6)

The protection of private patient information is commonly referred to as **confidentiality**. Confidentiality involves the protection of information revealed during patient-health care worker encounters, including all written or electronic records of these encounters. Confidentiality is an essential issue in many different aspects of TB control. Health care workers need to be aware of confidentiality issues that are relevant to patient-health care worker encounters as well as to the collection, management, and sharing of information gathered on TB patients.

Confidentiality is a very important issue in TB control because the diagnosis of TB disease is potentially damaging to patients. For some patients, a diagnosis of TB can lead to stigmatization or rejection by family, friends, and coworkers; the loss of a job; and possibly eviction from housing. In addition, the patient-health care worker relationship must be strong enough to last throughout the time it takes for a TB patient to complete adequate therapy.

### 7.2. List four specific confidentiality issues that require special attention by health care workers working with TB patients. (page 6)

There are some specific confidentiality issues that require special attention by health care workers working with TB patients:

- # The TB patient has certain rights that must be respected and are often protected by legislation
- # The health department has a responsibility to protect the public's health using certain effective TB control strategies
- # In the course of conducting TB control activities, some patient rights may be overridden in the interest of protecting the public's health (for example, an uncooperative, infectious patient may be quarantined until noninfectious)
- # Great care must be taken to ensure that patient rights — especially the right to privacy — are protected to the fullest extent possible so the patient-health care worker relationship is not compromised; this relationship must be strong enough to last throughout the time it takes a TB patient to complete adequate therapy



**7.3. What is the basis for the patient-health care worker relationship and why is it important in TB control? (page 8)**

The **patient-health care worker relationship** is the basis for

- # Sharing information
- # Communicating beliefs and feelings that affect care
- # Building trust between the patient and health care worker

The quality of this relationship is important in determining whether medical treatment is successful — particularly in TB control, where long-term adherence to a treatment regimen is critical. A strong patient-health care worker relationship built on trust and the preservation of patient confidentiality will increase the likelihood that the patient will be compliant and adhere to therapy.

**7.4. How is the patient-health care worker relationship like an agreement and what are some of the consequences if either party fails to conform to the agreement? (page 9)**

The patient-health care worker relationship can be viewed as an agreement between the patient and the health care worker. On the basis of the diagnosis, the health care worker recommends a given course of action and both parties (the patient and the health care worker) agree to work together to resolve the patient's health problem. The agreement incorporates some basic rules that each party will observe during the course of the relationship; such rules include respecting each other's rights and upholding certain responsibilities to each other and to other parties (such as the general public or the patient's contacts). If either the health care worker or the patient fails to conform to this agreement, the relationship can break down. This may lead to misunderstandings, a lapse in communication, and treatment failure.

**7.5. Who is considered a health care worker and who is the third party? What is the difference between the two? (pages 9-11)**

Health care worker refers to any member of a team of health professionals who care for and manage a TB patient, including

- # Physicians
- # Nurses
- # Outreach workers





- # Hospital discharge planners
- # Pharmacists
- # Social workers

A **third party** is a person or an organization not directly involved in the care of a patient's health problem. The work of a third party is peripheral to the patient-health care worker interaction.

The difference between a health care worker and a third party is that health care workers have access to patient information and can share patient information among members of the health care worker team in order to care for the patient. The only third parties who should have access to patient information are those whom the patient has specifically requested to be present during interviews or authorized to have access to records.

**7.6. Describe why trust is a key element in a successful patient-health care worker relationship and list three ways to develop trust.** (page 11)

Trust is the key to a successful patient-health care worker relationship in which the rights and responsibilities of both patient and health care worker are upheld. If a patient trusts or has confidence in his or her health care worker, he or she is more likely to be willing and able to adhere to a regimen and follow the health care worker's instructions and advice. Three ways to earn a patient's trust include

- # Respecting the patient's **autonomy**, the right of a patient to determine what will be done with his or her body, belongings, and personal information
- # Freely providing complete and accurate information
- # Rigorously maintaining confidentiality

**7.7. What are some serious consequences of revealing sensitive personal information to a third party without the patient's permission?** (page 12)

If sensitive personal information is revealed to a third party without the patient's permission, the patient's trust of the health care worker could be threatened and may result in serious consequences:

- # The patient-health care worker relationship may be damaged, possibly affecting the care of the patient
- # The patient may be stigmatized or rejected by family, friends, and others



- # The patient may lose a job or be evicted from housing
- # The health care worker may lose the trust of other patients

**7.8. What is an authorization or waiver form and when is it used?** (page 16-17)

The patient needs to give specific authorization or permission to allow a third party to have access to the patient's confidential information. Patients are asked to sign a specific waiver or form to allow their health information to be used by third parties. The patient has a right to refuse requests for information by third parties, as well as the right to limit the authorization in any way he or she wishes. TB programs and health care workers should carefully consider whether such requests are legitimate and valuable before asking patients to authorize disclosures.

**7.9. What is patient-identifiable information? List four specific uses for this information.** (page 19)

Personal information shared by the patient with his or her health care worker is considered "privileged" information; that is, information that the health care worker has a responsibility to protect. When the identify of the patient is either directly included in or can be deduced from such information, it is sometimes referred to as patient-identifiable information. This information is usually entered into the patient's medical record and into any secondary databases that are maintained by the health care worker or institution where the patient receives care. Secondary databases are usually maintained for the purposes of

- # Sharing information among members of the health care worker team
- # Conducting reporting and surveillance of diseases or medical conditions
- # Financing health care through reimbursements from the government or a private organization (such as an insurance company)
- # Conducting institutional review of the quality of care and appropriateness of expenditures

**7.10. What is informed consent?** (page 21)

The patient-health care worker relationship is founded on the patient's consent to the care being provided. Informed consent is a patient's written consent to a surgical or medical procedure or other course of treatment, given after the health care worker has told the patient all of the potential benefits, risks, and alternatives involved. The concept of informed consent is based on the principle that a health care worker has a duty to disclose information that allows the patient to make a reasonable decision regarding his or her own treatment.



**7.11. What are the four types of patient rights and what is the purpose of each of the patient rights?** (page 23)

Type of Patient Right	Purpose
The right to give or withhold authorization of disclosures	The patient generally has the right to control who has access to confidential information except as otherwise provided by law. The patient needs to give specific authorization or permission to allow a third party to have access to confidential information.
The right to maintain privacy	Only those persons directly involved in the care of the patient's health problem should have access to private information. Health care workers should protect information revealed during provider-health care worker encounters, including all written or electronic records of these encounters.
The right to have autonomy	Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information; this concept applies to any adult person who is mentally competent. Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions.
The right to be given information	The patient has a right to information about his or her medical diagnosis, treatment regimen, and progress. This allows the patient to make appropriate, informed decisions about his or her health care.

**7.12. What is due process and why is it important?** (page 23)

Due process is an established course for governmental activities or procedures designed to safeguard the legal rights of the individual. It is extremely important that an established course be followed so that all patients are treated equally and receive attention for their individual needs.



**7.13. Why is disclosure of patient information allowed for case reporting that is required by law? (page 29)**

Cases of TB are reported to federal, state, or local health authorities based upon laws governing the locality. Because TB is considered a significant threat to the public's health, the disclosure of the patient information from the health care worker to a designated public health authority is allowed for the purpose of TB control. In addition to routine case reporting, some TB control programs conduct active surveillance to identify TB cases through laboratory or pharmacy records. Health departments are required to protect the confidentiality of all TB case reports.

**7.14. How should health care workers protect confidentiality during DOT encounters? (page 32)**

DOT involves frequent encounters between the patient and health care worker, which may take place at sites in the community (for example, the patient's home, workplace, or other locations). Health care workers should make sure that the patient's confidentiality is protected during these encounters. This means that

- # The location chosen should allow private conversations
- # No other persons should be present without the patient's permission
- # Any documents or materials brought to such encounters should be protected from access by unauthorized persons

**7.15. What information should the health care worker explain to a patient regarding the protection of confidentiality during a contact investigation? (pages 34-35)**

When a contact investigation is to be conducted for a reported TB case, a health care worker should interview the patient, explain the goals of the investigation and why it is important to know the names of contacts. The patient should be told about his or her right to privacy and the measures that will be taken to maintain confidentiality.

The health care worker should be aware that some patients may be reluctant to identify some or all of their contacts. For example, a patient may not want to identify people who use illegal drugs with him or her, or the patient simply may not want his or her friends to know that he or she has TB. The health care worker should be sensitive to the patient's fears, explain the importance of screening the contacts, and assure the patient that all information, including the patient's name, will be kept confidential and will not be shared with authorities.



Finally, the patient should be assured that the contacts will not be told who identified them as a contact.

**7.16. What are some strategies that a health care worker can use to protect the TB case's (index case's) identity when conducting a contact follow-up during contact investigations? (page 36)**

Health care workers can use the following strategies to protect the confidentiality of the patient when conducting a contact follow-up during contact investigations:

- # Gender-neutral language should be used (even if it requires using bad grammar). For example, “Somebody was diagnosed with TB and they were [or “that person was”] concerned about you” instead of “A woman was diagnosed with TB and she was concerned about you.”
- # The index case's health care worker, place and dates of diagnosis, or hospitalization should not be mentioned
- # The environment in which the exposure occurred should not be mentioned. For example, “You have been around somebody who has TB” instead of “You have been around somebody at work who has TB.”
- # The dates of exposure should not be specified
- # When following-up on interjurisdictional referrals, the county or state that initiated the referral should not be mentioned
- # Confidentiality should not be violated even if contacts refuse to be evaluated until they have been told the index patient's identity

**7.17. Explain how other program activities, especially those involving data collection and analysis, require adequate measures to provide data security and protect confidentiality. (pages 39-41)**

Confidentiality is important when collecting and analyzing data with patient-identifiable information. TB control programs develop specific policies to ensure the security and confidentiality of TB records and should train staff members in procedures for maintaining and carrying out these policies. Policies and procedures should be in place to protect all TB reports, records, and files containing patient names or other identifying information.

Local policies regarding the security and confidentiality of such information, especially HIV test results, must adhere to all laws applicable in state and local jurisdictions.



These protections should include the use of TB surveillance databases such as CDC's Tuberculosis Information Management System (TIMS) software or other databases developed specifically for TB surveillance. These databases are encrypted to protect information during transfers of data for reporting purposes. Although such databases allow for the collection and storage of personal identifiers such as names and street addresses for local and state TB surveillance purposes, these identifiers are not transmitted to CDC. In general, any surveillance information sent through the mail should be stamped "confidential," addressed to a specific person (or sent to that person's attention), and sent by secure mail. These precautions will help to limit unauthorized access to surveillance information.

**7.18. List the ways in which a patient's confidentiality can be protected in the following situations.** (page 53)

**Any situation**

- # Confirm the patient's identity at the first encounter
- # Never discuss the patient's case with anyone without the patient's permission (including family and friends during off-duty hours)
- # Never leave hard copies of forms or records where unauthorized persons may access them
- # Use only secure routes to send patient information (for example, official mail) and always mark this information confidential
- # When using an interpreter, ensure that the interpreter understands the importance of patient confidentiality

**When in an office, clinic, or institution**

- # Conduct patient interviews in private rooms or areas
- # Never discuss cases or use patients' names in a public area
- # If a staff member or health care worker requests patient information, establish his or her authority to do so before disclosing anything
- # Keep records that contain patient names and other identifying information in closed, locked files
- # Restrict access to electronic databases to designated staff



- # Carefully protect computer passwords or keys; never give them to unauthorized persons
- # Carefully safeguard computer screens
- # Keep computers in a locked or restricted area; physically or electronically lock the hard disk
- # Keep printouts of electronic information in a restricted or locked area; printouts that are no longer needed should be destroyed

**When in the field**

- # Be discreet when making patient visits
- # Conduct patient interviews in private; never discuss the case in a public place
- # Don't leave sensitive or confidential information in messages for the patient on a door; but if a message must be left on the door, it should be left in a sealed envelope, marked confidential, and addressed to a specific person
- # Don't leave sensitive or confidential information on an answering machine that other people can access
- # Don't leave sensitive or confidential information with a neighbor or friend, and be careful not to disclose the patient's condition when gathering information on his or her whereabouts



## ANSWERS TO CASE STUDIES

**7.1 Van is a cook at a local restaurant. He came to the health department after his girlfriend, Tanya, told him that she had been diagnosed with TB disease. After undergoing tests for TB, it was confirmed that Van also has TB disease. Van is not from the United States and does not have the proper documents to be working in this country. During the contact investigation interview, Van was reluctant to provide information on where he worked. He did not want to get his employer in trouble and he does not want to be reported to immigration authorities. Van was also afraid that if people at work found out that he had TB that he would lose his job. Finally, Van also admitted to injecting drugs with some friends once in awhile, but was reluctant to give their names because he didn't want his friends to know that he had TB. He was also afraid his friends might be reported to the police.**

**# Why is it important to protect Van's confidentiality?**

By bringing his health problem to the attention of a health care worker, Van has entrusted personal information to the health care worker. If sensitive personal information about Van is revealed to a coworker, friend, or acquaintance without Van's permission, there may be serious consequences.

- # His relationship with the health care worker may be damaged, possibly affecting his care
- # He may lose his job or be evicted from housing
- # He may be stigmatized or rejected by his friends, family, and others
- # The health care worker may lose the trust of other patients

**# What can the health care worker do to develop trust with Van?**

There are three ways to earn a patient's trust including

- # Respecting Van's autonomy, his right to determine what will be done with his body, belongings, and personal information
- # Freely providing complete and accurate information to him
- # Rigorously maintaining confidentiality





Van has a lot of fear that others (employer, friends) will find out about his TB disease. He is also afraid he will be reported to immigration authorities. Van should be reassured that the information he shares, as well as information regarding his diagnosis, will not be shared with others and that the health care worker will keep all information confidential.

**7.2 Mr. Alvin Jones is a patient with infectious TB disease who has been recently discharged from the hospital. While hospitalized, Mr. Jones was very sick and had no problems with taking his medication or undergoing diagnostic procedures. Now that he is back at home, he has stopped taking his medications, has missed two clinic appointments, and has continually refused to speak to the health care worker assigned to his case. After many attempts to inform Mr. Jones of his condition and the need for treatment, the health department finally obtained a court order requiring Mr. Jones to complete a directly observed therapy regimen. Mr. Jones, not wanting to get into legal problems, has reluctantly agreed to meet with the health care worker to establish a treatment plan.**

**# Why is the health department able to obtain a court order, despite Mr. Jones' wish to stop treatment?**

Sometimes the right to autonomy can be overridden in the interest of protecting others who may be harmed by the patient's decisions. This can happen in TB control when a patient with infectious or potentially infectious TB disease refuses treatment. Because Mr. Jones poses a significant health threat to other people, he can be ordered by a court to participate in and complete his DOT. If he does not comply with this order, he could be detained until treatment is completed, depending on the strength of state and local TB control laws in his jurisdiction.

**# What should be done to protect Mr. Jones' rights to autonomy, information, and privacy?**

Autonomy is the right of a patient to determine what will be done with his or her body, personal belongings, and personal information. Although Mr. Jones has been ordered to comply with treatment, he should be able to participate in decisions about how his treatment is carried out. Health department staff should discuss the treatment and adherence plans with Mr. Jones, allowing him to have some input into these plans whenever feasible.



Mr. Jones has a right to information about his medical diagnosis, treatment regimen, and progress, as well as a right to review the information in his medical records. The health care worker should be careful to follow due process in working with Mr. Jones and documenting his therapy.

In this situation, maintaining the confidentiality of Mr. Jones' information is critical. Although disclosure was necessary to obtain the court order, it should have been strictly limited to those public health authorities who needed the information. Any health department or law enforcement officials who are involved in enforcing Mr. Jones' order should take great care to protect his right to privacy. A breach of confidentiality in these circumstances can further undermine the patient-health care worker relationship and lead to continued resistance to adherence-promoting measures.

**7.3. Ms. Rita Ramirez, a young mother of two children, has been diagnosed with infectious TB. She is also infected with HIV, which she contracted through sexual contact with her current partner, an HIV-infected injection drug user. Ms. Ramirez works in a factory that assembles small parts for electronic appliances; there are over 250 workers at the plant. She is very concerned about her job security, having only recently begun work on a temporary basis. Ms. Ramirez has consented to a treatment plan including a DOT regimen and is willing to cooperate with the contact investigation. She will inform her household contacts, but does not want anyone at work to know she has TB disease.**

**# Why is it important to protect the confidentiality of Ms. Ramirez' information?**

By bringing her health problem to the attention of a health care worker, Ms. Ramirez has entrusted personal information to the health care worker. Both TB disease and HIV infection have some social stigma attached to them and have serious implications for the patient's health. If sensitive personal information is revealed to a coworker, friend, or acquaintance without Ms. Ramirez permission, there may be serious consequences:

- # Her relationship with the health care worker may be damaged, possibly affecting her care
- # She may lose her job or be evicted from housing
- # She may be stigmatized or rejected by her family, friends, or others
- # The health care worker may lose the trust of other patients



## # What steps should be taken to ensure that confidentiality is maintained?

Ms. Ramirez should be told about her right to privacy and the measures that will be taken to maintain confidentiality. The health care worker in this case should be sensitive to her fears, explain the importance of screening the contacts, and assure her that all information, including her name, will be kept confidential and will not be shared with authorities. Health department staff will have to inform the workers of their possible exposure and screen people in the workplace. This should be done with as much discretion as possible, usually after some negotiation with the employer about the best way of informing workers, offering screening (on-site if possible), and providing follow-up care. It should also be pointed out to the patient that the health department has no control over family members, friends, and others whom she informs of her diagnosis and their exposure; she should make sure these are people she trusts and should stress the need for them to be discreet with her personal information.

Because Ms. Ramirez is infected with HIV, the health care worker should explain who is considered a contact for the purpose of TB investigations and that both Ms. Ramirez's name and her HIV status will be kept confidential. HIV reports are held in strictest confidence and in many jurisdictions are protected by statute from subpoena. For clinical care purposes, however, HIV-related information should be shared between TB care providers and other health care providers in accordance with state and local laws.

**7.4 Rolando is a health care worker at a busy TB clinic. It is the end of very busy Friday afternoon. He is trying to wrap things up and go home after his extremely stressful week. He is going through the patient-related papers and forms he has been working on that day. He is on his way to put the papers and forms in the file cabinet when he is interrupted by a phone call from his babysitter. His babysitter explains that she has to leave early that day. Thinking it is an emergency, Rolando hastily hands over the files to his co-worker Sam in the clinic area. He asks Sam to put the files on his desk. Before getting a reply from Sam, he leaves. Sam was not very happy because he was just leaving himself. He ends up leaving the files on the table in the clinic, an area where other TB patients may see the files.**

## # What measures should Rolando have taken to protect patient confidentiality?

Rolando should have ensured that patient records that contain patient names and other identifying information are placed in a closed locked file cabinet. In addition, no papers should be exposed when workers are away from the work area, even for



brief periods of time. Health care workers have a duty to protect patient records from unauthorized access. Information should be kept in closed, locked file cabinets except when being processed by authorized officials.

**7.5 Another outreach worker, Janice, has been trying to contact her patient Jerry for several days. She has visited his home several times, and tried to call him on the telephone. One time when she visits Jerry's house she sees Jerry's neighbor. The neighbor tells Janice that Jerry just left. Janice introduces herself to Jerry's neighbor and explains that she is from the TB clinic in the health department and is looking for Jerry. She tells the neighbor that the reason she is looking for Jerry is that he has TB and has missed taking treatment for over 1 week. She also tells the neighbor that if she sees Jerry to please tell him that she has stopped by to see him. Finally, she leaves a message for Jerry on the door of his apartment. She does not have any envelopes for her letter but decides Jerry must really get her message and so she tapes it to his front door.**

**# Did Janice do anything that possibly threatens Jerry's confidentiality? What measures should she have taken to protect patient confidentiality?**

Yes. Janice revealed private information about Jerry to Jerry's neighbor without authorization. Janice must be discreet when making patient visits. She should not have disclosed Jerry's condition to Jerry's neighbor. Also, she should not have revealed that she was from the TB clinic in the health department. Janice could have gathered information on Jerry's whereabouts without revealing