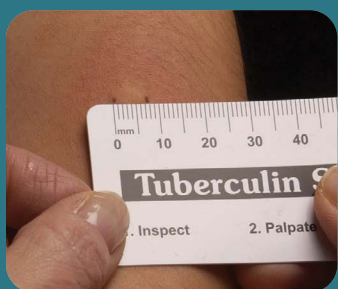




## Self-Study Modules on Tuberculosis



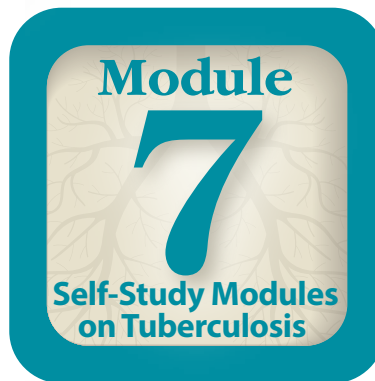
Module

7

# Patient Rights and Confidentiality in Tuberculosis Control





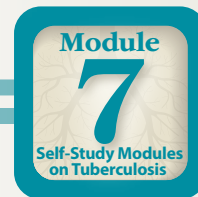


# Patient Rights and Confidentiality in Tuberculosis Control

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention  
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention  
Division of Tuberculosis Elimination

Atlanta, Georgia  
2014





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## Background

This module discusses patient rights and general recommendations for developing trust and maintaining confidentiality in the context of TB control.

Health care workers need to be aware of the importance of confidentiality issues involving patient-health care worker encounters, as well as to the collection, management, and sharing of TB patient data and information. In the treatment of TB disease and latent TB infection (LTBI), the relationship between the patient and the health care worker is extremely important. 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. Therefore, confidentiality—the protection of a patient's private information—is critical in TB control. By using the recommendations in this module, you should be able to protect the patient's rights and their confidentiality and help the TB program fulfill its responsibilities to the public.



## Objectives

After working through this module, you will be able to

1. Define confidentiality.
2. Explain why trust is important to a successful patient-health care worker relationship.
3. List four types of patient's rights.
4. Describe how confidentiality is an essential issue in several of the core components of a TB control program.



## New Terms

New terms introduced in this module are included below. Please refer to the *Self-Study Modules 1–5 Glossary* if you encounter unfamiliar terms related to TB that are not defined in the glossary below.

**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 all patient information, including patient records and information discussed or identified during patient-health care worker encounters

**court order**—an order issued by a court mandating an action such as compliance with directly observed therapy (DOT) or, in very rare cases, detention in a facility until treatment is completed

**data security**—protection of public health data and information systems to prevent unauthorized release of identifying information and accidental loss of data or damage to the systems. Security measures include measures to detect, document, and counter threats to data confidentiality or the integrity of data systems.

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

**Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule**—provides national standards for protecting the privacy of health information. The Privacy Rule regulates how organizations and health care workers use and disclose certain individually identifiable health information.



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

**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 a health care worker

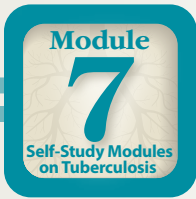
**protected health information (PHI)**—individually identifiable health information that is transmitted or maintained in a database; this can be electronic media or any other form or medium. The protected information must relate to 1) the past, present, or future physical or mental health condition of an individual; 2) provision of health care to an individual; or 3) payment for the provision of health care to an individual. If the information identifies or provides a reasonable basis to believe it can be used to identify an individual, it is considered individually identifiable health information.

**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

**TB health care worker**—any person who cares for and manages TB patients, including physicians, nurses, case managers, outreach workers, hospital discharge planners, pharmacists, social workers, peer educators, and volunteers

**third party**—a person or an organization not directly involved in the patient's care

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



## Introduction to Patient Rights and Confidentiality

Patient rights refer to certain basic rules of conduct between patients and any health care worker involved with the medical evaluation, treatment, or management of the patient. These rights need to be observed by all TB health care workers who are responsible for evaluating patients for TB infection or disease, treating and caring for any patient with latent TB infection (LTBI) or TB disease, and those health care workers involved in any other public health aspect of TB control.

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*TB health care workers must respect patient rights to ensure a successful patient-health care worker relationship.*

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There are three specific issues related to patient rights of which TB health care workers need to be aware:

- Patients have certain rights that are protected by law and must be respected;
- Patient confidentiality must be protected to maintain trust and preserve the patient-health care worker relationship; and
- Patient rights may sometimes be overridden to protect the public's health.

Many patient rights are protected by law to ensure that patients are treated with dignity and respect, and that they are empowered to be in charge of their own health. TB health care workers must respect these rights to ensure a successful patient-health care worker relationship. In the treatment of TB disease and LTBI, the relationship between the patient and the health care worker is extremely important.

Maintaining **confidentiality** is a key component of this relationship. Confidentiality refers to the protection of all patient information, including patient records and information discussed or identified during patient-health care worker encounters.

Although it is important to protect every patient's rights, there are times that health departments must also consider the interests of the public's health. Since health departments have a responsibility to protect the health of the public, some patient rights may need to be overridden to carry out TB control activities. For example, if a patient does not cooperate with the health care worker in completing treatment, the patient may need to continue treatment under a **court order** or be confined for the duration of treatment.

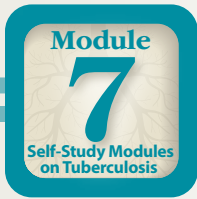


## Study Questions 7.1–7.2

**7.1** What is confidentiality?

**7.2** List three issues related to confidentiality and patient rights that health care workers need to be aware of.

*Answers to study questions are on pages 30–33*



## The Patient-Health Care Worker Relationship

### Who is Considered a TB Health Care Worker?

A **TB health care worker** is any person who cares for and manages a TB patient, including

- Physicians
- Pharmacists
- Nurses
- Social workers
- Case managers
- Peer educators
- Outreach workers
- Volunteers
- Hospital discharge planners

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*A TB health care worker is any person who cares for and manages a TB patient.*

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For TB patients, health care workers may include individuals from both public and private sectors. However, because the health department has ultimate responsibility for the TB cases in its jurisdiction, the health department should provide oversight of the management of all TB cases, including those seen in the private sector.

Health care workers from the public 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. Health care workers in the public sector should emphasize that because TB is considered a significant threat to the public's health, the disclosure of patient information from the private health care worker to a designated public health authority without the patient's permission or authorization is allowed for the purpose of TB control. For example, the **Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule** and most other medical data privacy laws allow disclosure of identifiable data from health care workers, data clearinghouses, and insurers to public health authorities without individual written authorization.

## 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 patient care
- Building trust between the patient and the health care worker

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*A strong patient-health care worker relationship is built on trust and the protection of confidentiality.*

---

The patient-health care worker relationship can be viewed as an agreement between the patient and the health care worker. This agreement includes basic rules that both the patient and the health care worker will observe during the course of their relationship, such as respecting each other's rights and upholding responsibilities. If either person fails to keep their agreement, misunderstandings, a lapse in communication, or treatment failure can occur.

## The Importance of Trust in the Patient-Health Care Worker Relationship

The quality of the patient-health care worker relationship is especially important in TB control, because long-term adherence to treatment is necessary. A strong patient-health care worker relationship is built on trust and the protection of confidentiality.

Trust means that the patient believes in the integrity, ability, and character of the health care worker. If there is trust between a patient and his or her health care worker, the patient may be more likely to adhere to treatment, name contacts, and follow the health care worker's instructions and advice. Therefore, health care workers should strive to gain a patient's trust by

- Maintaining confidentiality
- Providing complete and accurate information
- Respecting the patient's autonomy

Once developed, it is important to maintain trust. The patient may share personal information about lifestyle choices and risky, even potentially illegal behaviors, such as substance use. It is important that the health care worker assures the patient that personal information such as this will not be shared with authorities.

If personal information is revealed to others without the patient's permission, the patient's trust in the health care worker could be threatened and may result in serious consequences, such as the

- Patient-health care worker relationship may be damaged
- Health care worker may lose the trust of other patients and/or the community
- Patient may be stigmatized

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*If personal information is revealed to others without the patient's permission, the patient's trust in the health care worker could be threatened and may result in serious consequences.*

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## Study Questions 7.3–7.5

- 7.3 What does the patient-health care worker relationship serve as the basis for?
- 7.4 List three ways health care workers can develop trust with a patient.
- 7.5 Why is trust important to a successful patient-health care worker relationship?

*Answers to study questions are on pages 30–33*



## Case Study 7.1

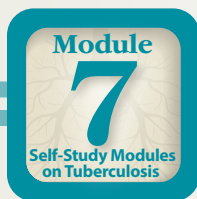
*Van is a cook at a local restaurant. He came to the health department after his girlfriend, Tanya, told him that she had been diagnosed with TB disease. After undergoing a complete medical evaluation, it was confirmed that Van also has TB disease.*

*Van is not from the United States and does not have the proper documents to be working in this country. During an interview with his health care worker, Van was reluctant to provide information on where he worked. He does not want to get his employer in trouble nor does he want to be reported to immigration authorities. Van was also afraid that if people at work found out that he had TB, he would lose his job. Finally, Van also admitted to injecting drugs with some friends occasionally, 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 personal information?**

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

*Answers to case studies are on pages 34–36*



## Patient Rights

Patients have certain rights concerning their personal information relevant to their medical care. These rights are explained below and summarized in Table 7.1.

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

---

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

---

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

**Disclosure** is the act of revealing or distributing personal information. Patients have the right to give or withhold **authorization** of disclosures. This means that the patient should have control over

- Who will receive his or her personal information
- What information should be released
- How long the authorization of disclosure will last

A patient discloses personal information to a health care worker so that he or she can receive appropriate treatment and care. Health care workers are allowed to share patient information with others directly involved in the management of the patient to provide quality care. For example, an outreach worker can discuss a patient's medication side effects with the clinic physician.

---

*The patient needs to give specific authorization to allow a third party access to their confidential information.*

---

Sometimes health care workers are asked by a **third party** to disclose patient information. A third party is a person or organization not directly involved in the patient's care (e.g., media or workplace). In these situations, health care workers are not allowed to disclose patient information. The patient needs to give specific authorization to allow a third party access to their confidential information. TB programs and health care workers should carefully consider if requests from third parties are legitimate before asking patients to authorize disclosures. To give authorization, patients are often asked to sign a **waiver** or a permission form. These documents should be carefully explained to patients. The patient has a right to refuse requests



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. A public health authority can disclose personal information if there is an overriding public health need.

Patient authorization is NOT needed for **passive case reporting**. Passive case reporting is the required reporting of suspected or confirmed TB cases to a public health authority.

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*Personal information shared by the patient with his or her health care worker is considered privileged information and should be protected.*

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## The Right to Maintain Privacy

Health care workers should protect information revealed during patient-health care worker encounters, including all written or electronic records of these encounters. Only those persons directly involved in the care of the patient 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 information and data. Personal information shared by the patient with his or her health care worker is considered **privileged information** and should be protected. 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 (e.g., an insurance company)
- Conducting institutional review of the quality of care and appropriateness of expenditures

When the patient's identity is either directly included in or can be deduced from such information, it is sometimes referred to as **patient-identifiable information**.

## The Right to Have Autonomy

**Autonomy** is the right of a patient to determine control over his or her body, personal belongings, and personal information. The concept of autonomy applies to any adult person who is mentally competent. The right to autonomy has some limitations designed to protect the patient. For example, if the patient is a child or a mentally incompetent adult, a parent or legal guardian typically acts as the decision maker.

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*Autonomy is the right of a patient to determine control over his or her body, personal belongings, and personal information.*

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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.*

---

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 TB disease refuses treatment. Because the patient poses a significant health risk to the public, he or she may receive a **court order** which mandates directly observed therapy (DOT) or, in rare cases, detention in a facility until treatment is completed. (For more information on legal remedies to nonadherence, refer to *Module 6, Managing Tuberculosis Patients and Improving Adherence*.) Health departments should contact their legal counsel for guidance on this process.

With the exception of the situations mentioned above, autonomy means that health care workers should respect patient decisions about their health care.

### **The Right to Be Given Information**

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

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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 informed decisions about his or her health care. For example, a patient with TB disease has a right to know the treatment options available, the duration of treatment, potential side effects of the drugs, and the expected outcome. This information may be valuable to the patient not only for making health care decisions, but also for making decisions about other important issues such as housing or family matters.

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

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The patient also has a right to review the information in his or her medical record. The 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. 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, the patient can usually file a **statement of disagreement**. The documentation of a patient's medical history is very important and can affect current and future medical decisions for the patient. Therefore, it is important that it be as accurate and objective as possible when documenting patient information.

**Table 7.1 Summary of Patient Rights**

| Type of Patient Right                                      | Description   |
|--|---|
| 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 required by law. The patient needs to give specific authorization to allow a third party to have access to confidential information. However, a public health authority can disclose personal information if there is an overriding public health need. |
| The right to maintain privacy                              | Only persons directly involved in the care of the patient should have access to private information. Health care workers should protect all patient information.  |
| The right to have autonomy                                 | Autonomy is the right of a patient to determine control over 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 informed decisions about his or her health care.  |



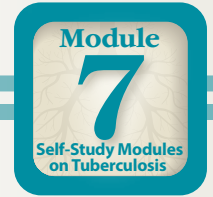
## **Study Questions 7.6–7.8**

**7.6** List four types of patient’s rights.

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

**7.8** What is patient-identifiable information?

*Answers to study questions are on pages 30–33*



## TB Control and Confidentiality

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*It is the responsibility of health care workers to protect patient information.*

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*Health care workers should become familiar with the confidentiality laws in their jurisdiction.*

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Confidentiality is essential in many aspects of TB control, including patient-health care worker encounters, as well as the collection, management, and sharing of TB patient data and information. It is the responsibility of health care workers to protect patient information and to make sure that only persons directly involved in patient care or public health activities have access to patient information. If patient information is disclosed to unauthorized persons without the patient's permission, the patient may be stigmatized or experience rejection from family, friends, and others. Great care must be taken to ensure that patients' rights to privacy are protected to the fullest extent possible such that the patient-health care worker relationship is not compromised. Additionally, it is important for health care workers to maintain confidentiality and have a good relationship with patients to ensure they do not lose the trust of the community as a whole. This is particularly important in small, close-knit communities.

Multiple laws and regulations exist to protect data security and confidentiality. For example, the **Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule** generally prohibits the use or disclosure of **protected health information (PHI)** without written authorization from the patient. There are several exceptions to this requirement, including an exception for public health. PHI can be disclosed to public health authorities for public health purposes including, but not limited to, public health surveillance, investigations, and interventions. Additionally, each state may have its own laws regarding security and confidentiality of patient information. Health care workers should become familiar with the confidentiality laws in their jurisdiction.

Confidentiality must be preserved in the following TB control activities:

- Ensuring adequate patient care
- Performing contact investigations
- Collecting and analyzing data
- Conducting program evaluation
- Referring patients to other jurisdictions

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*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.*

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## Ensuring Adequate Patient Care

The most effective strategy to ensure patients adhere to TB treatment is directly observed therapy (DOT). This method of treatment involves frequent meetings between the patient and the health care worker. These meetings take place at locations that are convenient for the patient. Health care workers should make sure that the patient's confidentiality is protected during these encounters. This means that

- The location should allow for privacy
- Other persons should not be present without the patient's permission

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

- Review the potential causes of the patient's nonadherence
- Identify potential solutions
- Meet the patient's needs to assist completion of therapy

If these measures fail, the patient may be required to continue treatment under a court order or be isolated until noninfectious. Although disclosure of patient information is necessary to obtain a court order or an order for confinement, such disclosure should be limited to the appropriate authorities who need the information. Any health department or law enforcement officials who become involved should take care to protect the patient's right to privacy. A breach of confidentiality in these circumstances can undermine the patient-health care worker relationship and lead to continued problems with adherence. (For more information about addressing nonadherence, refer to *Module 6, Managing Tuberculosis Patients and Improving Adherence.*)

## Performing Contact Investigations

When a case of infectious TB disease is reported, a contact investigation should be conducted to identify persons who may have been in contact with that person and to assess those persons for TB infection and TB disease. (For more information about TB contact investigations, refer to *Module 8, Contact Investigations for Tuberculosis*.)

To conduct a contact investigation, health care workers interview the patient to get information about where the patient spent time and who they spent time with while infectious. The health care worker should ensure that interviews with the patient take place in private. Health care workers should emphasize confidentiality, yet inform the patient that relevant information may need to be shared with other health department staff who have a need to know. Additionally, if the patient spent time in a congregate setting (e.g., a school or shelter) while infectious, the health care worker should inform the patient that an appropriate site manager (e.g., school principal or supervisor) may need to be notified such that they can assist in accurately and efficiently identifying contacts who need to be evaluated. If the patient's identity is revealed to a site manager, the health department should obtain a signed confidentiality agreement from the site manager.

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*Confidentiality should not be violated even if contacts refuse to be evaluated.*

---

The health care worker should be careful not to inadvertently reveal clues about the TB patient's identity while meeting with the patient's contacts. **Confidentiality should not be violated even if contacts refuse to be evaluated.** The following strategies can be used to protect the confidentiality of the patient when meeting with contacts:

- Use gender-neutral language. For example, “Someone you have spent time with was diagnosed with TB and they were concerned about you” instead of “A woman you have spent time with was diagnosed with TB and she was concerned about you.”
- Do not mention the patient's health care worker, place and dates of diagnosis, or hospitalization history.
- Do not mention the environment in which the exposure occurred. For example, “You have been around someone who has TB” instead of “You have been around someone at work who has TB.”
- Do not confirm the name of the patient if the contact correctly guesses his or her identity.

---

*Patients should be informed that despite best efforts, sometimes confidentiality is not preserved.*

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Patients should be informed that sometimes despite best efforts, their TB status may be inadvertently disclosed to others. For example, a friend, family member, or co-worker of the patient may share information about the patient to others. The patient and the health care worker should discuss this possibility and be prepared to address the situation in the event that privacy is not maintained. To prevent breaches in confidentiality, patients should be advised to inform only persons they trust about their TB diagnosis.

## Collecting and Analyzing Data

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*Data security is the protection of public health data and information systems to prevent unauthorized release of identifying information and accidental loss of data or damage to the systems.*

---

An important part of confidentiality is **data security**. Data security is the protection of public health data and information systems to prevent unauthorized release of identifying information and accidental loss of data or damage to the systems. Security measures include measures to detect, document, and counter threats to data confidentiality or the integrity of data systems.

All 50 states and the District of Columbia mandate that physicians and other health care providers report newly diagnosed cases of TB to the state health department. State health departments report this TB surveillance data to CDC under an agreement between the CDC and the Council of State and Territorial Epidemiologists (CSTE).

The disclosure of patient information to a designated public health authority is allowed without written authorization from the patient because TB is considered a significant threat to public health. Health departments are required to comply with privacy laws intended to keep TB patient information confidential.

---

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

---

Security and confidentiality is particularly important when collecting and analyzing data with identifiable (e.g., names and addresses) and potentially identifiable (e.g., dates of birth, lab report dates, immigration status, county, or age greater than 89) patient information. TB control programs should develop specific policies to ensure the security and confidentiality of TB records. For example, policies and procedures should be in place to protect all TB reports, records, and files containing patient names or other identifying information. Data security and confidentiality guidelines were developed by the CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention in 2011 as a reference for states implementing data confidentiality policies. These guidelines are available at [www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf](http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf). Staff



members should have a clear understanding of these and other existing state and local data security and confidentiality requirements.

National Electronic Disease Surveillance System (NEDSS)-compliant systems such as the NEDSS Base System (NBS) Tuberculosis Program Area Module (TB PAM) or the Electronic Report of Verified Case of Tuberculosis (eRVCT) should be used to maintain the security and confidentiality of data. These surveillance systems encrypt protected information during transfers of data to CDC for national surveillance purposes. Although these systems 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. These precautions help to limit unauthorized access to surveillance information.

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*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.*

---

Because HIV/AIDS can have serious implications for TB care and treatment, some health jurisdictions have additional confidentiality 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. 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.

TB programs often collaborate with HIV/AIDS programs to conduct annual TB and HIV/AIDS registry matches to ensure completeness of reporting for HIV and TB coinfecting patients. These TB programs should adhere to the same confidentiality standards as HIV/AIDS surveillance programs and should work with local HIV/AIDS programs to establish equivalent data security and confidentiality policies.

## Conducting Program Evaluation

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

- Morbidity rates
- Trends
- Demographic characteristics of TB patients in the area

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

---

Evaluation reports 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, such as names, addresses, or detailed demographic information that could be used to identify the patient.

## Referring Patients to Other Jurisdictions

---

*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 information is given to the receiving jurisdiction, to ensure the patient continues their TB care and treatment. Health care workers should be aware that confidentiality and security laws and procedures may vary from state to state. (For more information about interjurisdictional referrals, refer to *Module 6, Managing Tuberculosis Patients and Improving Adherence*.)

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*When sending information via mail, email, or fax, measures should be taken to ensure confidentiality.*

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Although sharing 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. Confidential information should be transferred via secure electronic methods, personal communication, or hard-copy mail delivery whenever possible. When sending information via mail, email, or fax, measures should be taken to ensure confidentiality. For example, any materials sent through the mail should be sent directly to a specific person and, if possible, with added security such as signature confirmation, restricted delivery, or certified mail. Health care workers should never fax patient information if they are unsure that the receiving fax machine is in a secure area. All information sent by fax or email should be sent to a specific person and labeled confidential. Never send any information with patient-identifiable information through email without encryption.



## **Study Questions 7.9–7.12**

- 7.9** List two ways health care workers can protect patient confidentiality during DOT encounters.
- 7.10** List four strategies health care workers can use to protect patient confidentiality when conducting contact investigations.
- 7.11** Why is disclosure of patient information allowed for routine case reporting?
- 7.12** How can health care workers ensure security and confidentiality when referring patients to other jurisdictions?

*Answers to study questions are on pages 30–33*



## Case Study 7.2

*Miranda is a high school student who was recently diagnosed with infectious TB disease. During an interview with her health care worker, she reported that she rides the bus to school every day and participates in a few extracurricular activities. Miranda was reluctant to provide additional information about her contacts because she did not want anyone at school to know she has TB.*

**How should the health care worker respond to Miranda’s concerns about confidentiality?**

**One of Miranda’s classmates refuses to be evaluated without knowing the identity of the person who may have infected them. What should the health care worker do in this situation?**

*Answers to case studies are on pages 34–36*

## Measures to Protect Patient Confidentiality and Ensure Data Security

### Measures to Protect Patient Confidentiality

Health care workers should take the following measures to protect patient confidentiality when meeting with a patient

- Confirm the patient's identity at the first encounter
- Conduct patient interviews in private (Figure 7.1)
- Ensure interpreters understand the importance of confidentiality

After meeting a patient, health care workers should

- Never discuss the patient's case with anyone without the patient's permission (unless there is a public health need)
- Never discuss cases or use patient names in a public area
- Use only secure routes to send patient information and always mark as confidential



Figure 7.1 Conducting patient interviews in privacy.

## Ensuring Data Security and Confidentiality in an Office, Clinic, or Institution

Data security is also an important aspect of confidentiality. Care should be taken to ensure the safeguarding of patient information in an office, clinic, or institution.

- 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 (Figure 7.2). Never leave hard copies of forms or records where unauthorized persons may access them.
- Restrict access to electronic databases to designated staff.
- Carefully protect computer passwords; never give them to unauthorized persons.
- Keep computers in a locked or restricted area; password protect computers.
- Keep printouts of electronic information in a restricted or locked area; printouts that are no longer needed should be shredded.

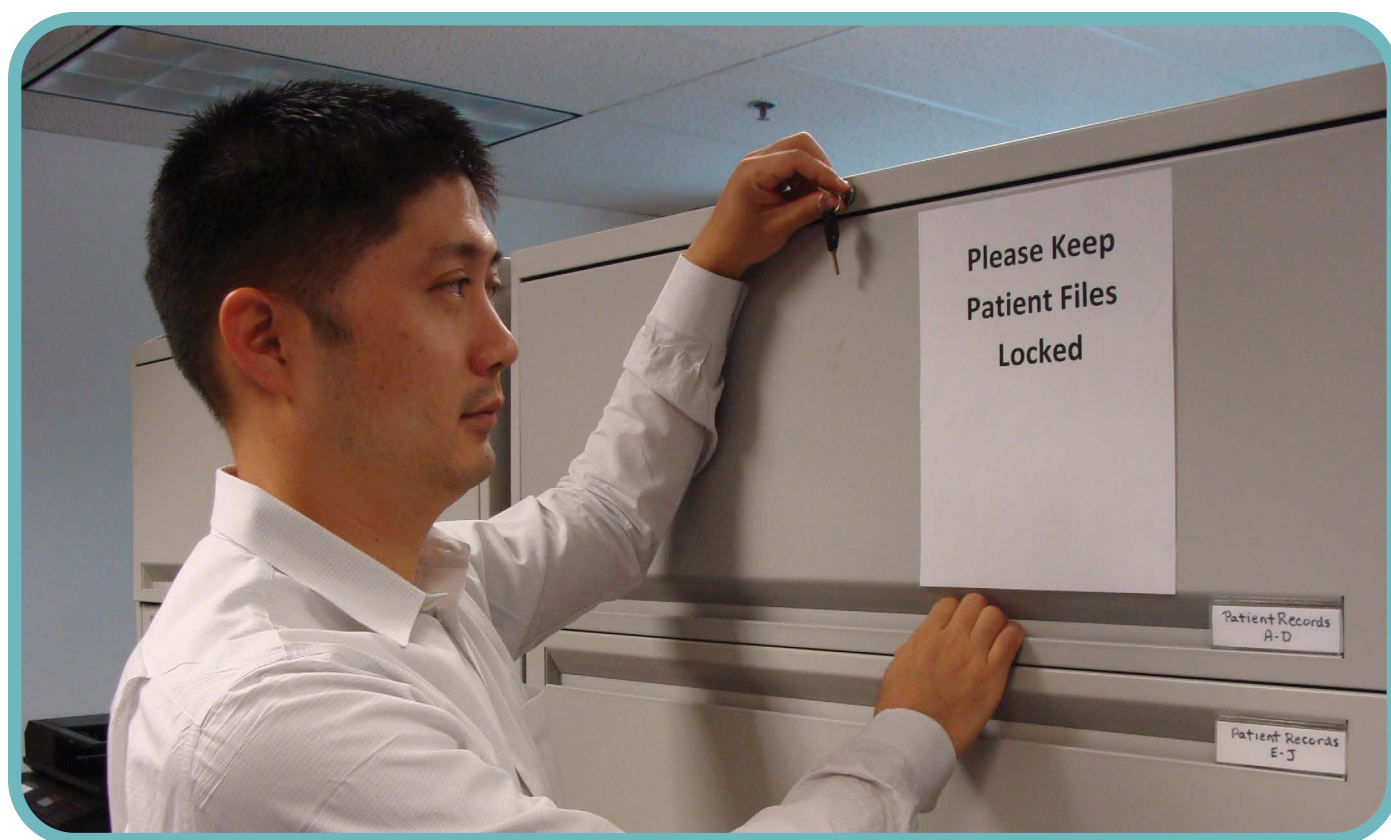


Figure 7.2 Closed, locked files.

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

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

- Medical records
- Report of Verified Case of Tuberculosis (RVCT) forms
- Communicable disease report cards
- Other records that contain patient names and other identifying information

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 this information should be restricted to designated TB program staff who are directly involved with surveillance or 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.

## **Protecting Confidentiality in the Field**

When conducting field visits, health care workers may need to ask for patients by name or ask about a patient's work location and habits. This should be done as discreetly as possible. For example, a health care worker could ask for a patient by name but should not explain that they are from the TB Program.

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*In the field, there are important measures that can be taken to protect patient confidentiality.*

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In the field, there are important measures that can be taken to protect patient confidentiality:

- Conduct patient interviews in private; never discuss the case in a public place.
- Do not leave confidential information in messages for the patient on a door.
- Do not leave confidential information on an answering machine.
- Do not leave confidential information with a neighbor or friend.
- Do not disclose the patient's condition when gathering information on his or her whereabouts.



## Study Questions 7.13–7.15

- 7.13** List three general measures to protect patient confidentiality.
- 7.14** List four ways to ensure data security in the office, clinic, or institution.
- 7.15** List four measures health care workers can take to protect confidentiality while working in the field.

*Answers to study questions are on pages 30–33*





## Case Study 7.3

*Rolando is a health care worker at a 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 forms he has been working on that day. He is on his way to put the 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 also just about to leave. He ends up leaving the files on the table in the clinic, an area where other patients may see the files.*

**What measures should Rolando have taken to ensure security and confidentiality?**

*Answers to case studies are on pages 34–36*



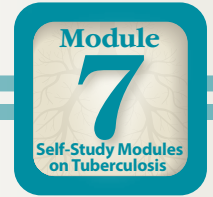
## Case Study 7.4

*Janice is an outreach worker at a TB clinic. She has been trying to contact her patient Jerry for several days. She has visited his home several times and tried to call him. 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 if she sees Jerry, please tell him that she has stopped by to see him. Finally, she leaves a message for Jerry on the front door of his house. She does not have any envelopes for her letter, but decides Jerry must really get her message and so she tapes it to his door.*

**Did Janice do anything that possibly threatens Jerry's confidentiality?**

**What measures should Janice have taken to protect Jerry's confidentiality?**

*Answers to case studies are on pages 34–36*



## Additional Resources

1. CDC. Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action. Atlanta, GA: Department of Health and Human Services, CDC; 2011. [www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf](http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf).
2. CDC. Frequently Asked Questions About HIPAA Privacy Rule: Provisions Relevant to Public Health Practice. Atlanta, GA: Department of Health and Human Services, CDC; 2013. [www.cdc.gov/nhsn/faqs/FAQ\\_HIPPARules.html](http://www.cdc.gov/nhsn/faqs/FAQ_HIPPARules.html).
3. CDC. HIPAA Privacy Rule and Public Health: Guidance from CDC and the U.S. Department of Health and Human Services. MMWR 2003; 52 (S-1): 1–12. [www.cdc.gov/mmwr/preview/mmwrhtml/su5201a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/su5201a1.htm).
4. CDC. Privacy Legislation and Regulations. Atlanta, GA: Department of Health and Human Services, CDC; 2010. [www.cdc.gov/od/science/integrity/privacy](http://www.cdc.gov/od/science/integrity/privacy).
5. CDC. Tuberculosis Control Laws—United States, 1993: recommendations of the Advisory Council for the Elimination of Tuberculosis (ACET). MMWR. 1993;42(RR-15):1–28. <http://www.cdc.gov/mmwr/preview/mmwrhtml/00030715.htm>.



## Answers to Study Questions

### 7.1 What is confidentiality?

Confidentiality is the protection of all patient information, including patient records and information discussed or identified during patient-health care worker encounters.

### 7.2 List three issues related to confidentiality and patient rights that health care workers need to be aware of.

Three specific issues related to confidentiality and patient rights that health care workers need to be aware include

- Patients have certain rights that are protected by law and must be respected;
- Patient confidentiality must be protected to maintain trust and preserve the patient-health care worker relationship; and
- Patient rights may sometimes be overridden to protect the public's health.

### 7.3 What does the patient-health care worker relationship serve as the basis for?

The patient-health care worker relationship is the basis for

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

### 7.4 List three ways health care workers can develop trust with a patient.

Health care workers should strive to gain a patient's trust by

- Maintaining confidentiality
- Providing complete and accurate information
- Respecting the patient's autonomy

### 7.5 Why is trust important to a successful patient-health care worker relationship?

Trust means that the patient believes in the integrity, ability, and character of the health care worker. If there is trust between a patient and his or her health care worker, the patient may be more likely to adhere to treatment, name contacts, and follow the health care worker's instructions and advice. Once developed, it is important to maintain trust. The patient may share personal information about lifestyle choices and risky, even potentially illegal behaviors, such as substance use. It is important that the health care worker assures the patient that personal information such as this will not be shared with authorities.



## Answers to Study Questions, Continued

If personal information is revealed to others without the patient's permission, the patient's trust in the health care worker could be threatened and may result in serious consequences, such as the:

- Patient-health care worker relationship may be damaged
- Health care worker may lose the trust of other patients and/or the community
- Patient may be stigmatized

### 7.6 List four types of patient's rights.

- The right to give or withhold authorization of disclosures
- The right to maintain privacy
- The right to have autonomy
- The right to be given information

### 7.7 What is an authorization form or waiver and when is it used?

An authorization form or waiver is a document that patients sign in order to allow a third party access to their confidential information. These documents should be carefully explained to patients. The patient has a right to refuse requests 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 if requests from third parties are legitimate before asking patients to authorize disclosures.

### 7.8 What is patient-identifiable information?

Patient-identifiable information is when the patient's identity is either directly included or can be deduced from the information.

### 7.9 List two ways health care workers can protect patient confidentiality during DOT encounters.

Health care workers should make sure that the patient's confidentiality is protected during DOT encounters. This means that

- The location should allow for privacy
- Other persons should not be present without the patient's permission



## Answers to Study Questions, Continued

### 7.10 List four strategies health care workers can use to protect patient confidentiality when conducting contact investigations.

The health care worker should ensure that contact investigation interviews with the patient take place in private.

The health care worker should also be careful not to reveal identifying clues about the TB patient while meeting with the patient's contacts. Confidentiality should not be violated even if contacts refuse to be evaluated. The following strategies can be used to protect the confidentiality of the patient when meeting with contacts:

- Use gender-neutral language. For example, “Someone you have spent time with was diagnosed with TB and they were concerned about you” instead of “A woman you have spent time with was diagnosed with TB and she was concerned about you.”
- Do not mention the patient's health care worker, place and dates of diagnosis, or hospitalization.
- Do not mention the environment in which the exposure occurred. For example, “You have spent time with someone who has TB” instead of “You have spent time with someone at work who has TB.”
- Do not confirm the name of the patient if the contact correctly guesses his or her identity.

### 7.11 Why is disclosure of patient information allowed for routine case reporting?

The disclosure of patient information to a designated public health authority is allowed for routine case reporting without written authorization from the patient because TB is considered a significant threat to public health. Health departments are required to comply with privacy laws intended to keep TB patient information confidential.

### 7.12 How can health care workers protect patient confidentiality when referring patients to other jurisdictions?

Confidential information should be transferred via secure electronic methods, personal communication, or hard-copy mail delivery when possible. When sending information via mail, email, or fax, measures should be taken to ensure confidentiality. For example, any materials sent through the mail should be sent directly to a specific person and, if possible, with added security such as signature confirmation, restricted delivery, or certified mail. Health care workers should never fax patient information if they are unsure that the receiving fax machine is in a secure area. All information sent by fax or email should be sent to a specific person and labeled confidential. Never send any information with patient-identifiable information through email without encryption.



## Answers to Study Questions, Continued

### 7.13 List three general measures to protect patient confidentiality.

Measures health care workers can take to protect patient confidentiality include:

- Confirm the patient's identity at the first encounter.
- Conduct patient interviews in private.
- Ensure interpreters understand the importance of confidentiality.
- Never discuss the patient's case with anyone without the patient's permission.
- Never discuss cases or use patient names in a public area.
- Use only secure routes to send patient information and always mark as confidential.

### 7.14 List four ways to ensure data security in the office, clinic, or institution.

Health care workers can ensure data security by doing the following:

- 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. Never leave hard copies of forms or records where unauthorized persons may access them.
- Restrict access to electronic databases to designated staff.
- Carefully protect computer passwords; never give them to unauthorized persons.
- Keep computers in a locked or restricted area; password protect computers.
- Keep printouts of electronic information in a restricted or locked area; printouts that are no longer needed should be shredded.

### 7.15 List four measures health care workers can take to protect confidentiality while working in the field.

In the field, there are important measures that can be taken to protect patient confidentiality:

- Conduct patient interviews in private; never discuss the case in a public place.
- Do not leave confidential information in messages for the patient on a door.
- Do not leave confidential information on an answering machine.
- Do not leave confidential information with a neighbor or friend.
- Do not disclose the patient's condition when gathering information on his or her whereabouts.



## Case Study Answers

**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 a complete medical evaluation, 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 an interview with his health care worker 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, he would lose his job. Finally, Van also admitted to injecting drugs with some friends occasionally, 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 personal information?**

If personal information is revealed to others without Van's permission, his trust in the health care worker could be threatened and may result in serious consequences, such as:

- The patient-health care worker relationship may be damaged
- The health care worker may lose the trust of other patients and/or the community
- Van may be stigmatized

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

The health care worker should strive to gain Van's trust by:

- Maintaining confidentiality
- Providing complete and accurate information
- Respecting Van's autonomy

Once developed, it is important to maintain trust. The health care worker should assure Van that personal information, such as injecting drugs, will not be shared with authorities.





## Case Study Answers, Continued

**7.2** *Miranda is a high school student who was recently diagnosed with infectious TB disease. During an interview with a health care worker, she reported that she rides the bus to school every day and participates in a few extracurricular activities. Miranda was reluctant to provide additional information on her contacts because she did not want anyone at school to know she has TB.*

### **How should the health care worker respond to Miranda’s concerns about confidentiality?**

The health care worker should tell Miranda that all of her personal information will be kept as confidential as possible. Since Miranda is in school, it may be necessary for the health care worker to inform an appropriate site manager (e.g., the school principal) such that they can assist in accurately and efficiently identifying contacts who need to be evaluated. The health care worker should tell Miranda that if this needs to happen, the health department will obtain a signed confidentiality agreement from the site manager.

The health care worker should tell Miranda that he or she will not reveal her name or any clues about her while meeting with contacts.

### **One of Miranda’s classmates refuses to be evaluated without knowing the identity of the person who may have infected them. What should the health care worker do in this situation?**

The health care worker should not violate Miranda’s confidentiality even if one of her contacts refuses to be evaluated. Additionally, the health care worker should not confirm Miranda’s name even if the contact correctly guesses her identity.



## Case Study Answers, Continued

**7.3** *Rolando is a health care worker at a 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 forms he has been working on that day. He is on his way to put the 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 also just about to leave. He ends up leaving the files on the table in the clinic, an area where other 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 were 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.

**7.4** *Janice is an outreach worker at a TB clinic. She has been trying to contact her patient Jerry for several days. She has visited his home several times and tried to call him. 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 if she sees Jerry, please tell him that she has stopped by to see him. Finally, she leaves a message for Jerry on the front door of his house. She does not have any envelopes for her letter, but decides Jerry must really get her message and so she tapes it to his door.*

### **Did Janice do anything that possibly threatens Jerry's confidentiality?**

Yes. Janice revealed private information about Jerry to his neighbor without his permission.

### **What measures should Janice have taken to protect Jerry's confidentiality?**

Janet should not have revealed to Jerry's neighbor that she was from the TB clinic in the health department. Janice could have gathered information on Jerry's whereabouts without revealing sensitive information to his neighbor. Finally, Janice should not have left the letter on Jerry's door.



