

4 How Well Do You Know Your Environment?

Understanding your program area's environment will help you to anticipate and minimize potential challenges to TB prevention and control. It will also help you to identify new sources of support.

Demographic Information on Your Program Area

Demographic information refers to the vital statistics of your program area's population. These statistics include birth rates, death rates, country of origin, ethnicity, and age. Monitoring your program area's demographic trends allows you to identify and prepare for population changes that are likely to impact your TB program.

Demographic information is often easily obtained from specific county and state agencies tasked with monitoring demographics, school districts, and refugee and immigration programs. Information can also be obtained from the United States Census Bureau. The U.S. Census Bureau Website contains information by state and county and can be accessed electronically at www.census.gov.

Six Categories of Effective TB Environmental Monitoring and Analysis

- Demographic information on your program area
- TB epidemiological profile of your program area
- Information on your program area's at-risk populations
- Understanding primary care providers in your program area
- Comparing your data to your TB program
- Identifying and understanding additional stakeholders

Epidemiological Profile of Your Program Area

Using your surveillance data to create a comprehensive epidemiological profile of your program area is an essential first step toward effectively addressing TB. Your epidemiological profile tells you how TB is manifesting itself in your program area by categorizing TB disease trends by

- Age
- Ethnicity
- Country of origin
- Length of time in the United States
- Geographic location
- Treatment completion rates
- Drug resistance
- DNA fingerprinting
- Latent TB infection rates of at-risk populations

In low-caseload, low-incidence states, analyses of annual trends can be inconclusive. These states may find it helpful to review changes over 5-year spans and undertake the ongoing systematic review of TB cases with the following features: <15 years of age; drug-resistant *M. tuberculosis* isolates; extensive or advanced TB disease, which is suggestive of delays in diagnosis; or deaths before patients complete treatment.⁴¹

What an Epidemiological Profile Revealed: Immigrants & Refugees	
Subject	African Immigrants and Refugees, Based on Active Disease Data Collected from 1998 through 2001
Location	Seattle-King County
Source	MMWR October 4, 2002.
Significant Findings	
<p>The overall rate of TB in Seattle-King County was 8 cases per 100,000 population during the period studied. The annual rate of TB for African immigrants in Seattle-King County was 262 per 100,000, a figure matching the WHO estimates for the African nations involved.</p> <p>TB cases among African immigrants and refugees rose annually, with this population accounting for 20% of TB cases in Seattle by 2001. The majority of TB cases (85%) were among individuals from the African Horn countries of Eritrea, Ethiopia, and Somalia. Of known TB cases in Seattle among persons from Africa, 45% occurred within the first year of arrival in the United States, and 65% within the first 5 years, a much higher figure than for other at-risk immigrant populations.</p> <p>The median age of African immigrants with TB was 27 years; 53% had extrapulmonary disease. Characteristics of patients and of TB disease were similar for all immigrants from Africa.</p>	
Response	
Programs Implemented	<p>Worked with primary health care providers and civil surgeons to raise awareness of the high TB rates among African immigrants, especially within the first 5 years of arrival, and of the severe extrapulmonary forms of TB present in the population</p> <p>In 1999, a flexible community-based approach to TB prevention and control was implemented. It includes partnerships with immigrant service systems, engages groups of immigrants in an exchange of TB information, and employs immigrants to serve as outreach workers in their communities. The outreach workers visit patients undergoing treatment for both LTBI and TB disease, serve as mediators between patients and their health-care providers, and assist with resettlement issues such as education, housing, and overall health care.</p>
Program Outcomes	<p>TB treatment acceptance among targeted refugees increased from 51% to 86% within 2 years.</p> <p>TB treatment completion rates increased from 50% to 87% within 2 years.</p>

⁴¹CDC. Progressing toward tuberculosis elimination in low-incidence areas of the United States: recommendations of the Advisory Council for the Elimination of Tuberculosis. *MMWR* 2002; 51 (No. RR-5:10).

What an Epidemiological Profile Revealed: Multidrug-Resistant Tuberculosis	
Subject	MDR TB
Location	St. Louis, MO
Source	TB Notes No. 2, 2001
Significant Findings	
<p>From 1998 to 2001, nine cases of <u>MDR TB</u> were found in St. Louis. The Missouri Department of Health invited the CDC to assist with identifying the MDR TB Cluster. Significant findings included:</p> <p>The CDC investigators were able to link six cases in the cluster. Seven of the cases were part of the same social network. Prior to the arrival of the CDC, only three cases had been linked.</p> <p>An index case was identified with risk factors that included homelessness, alcohol dependence, and other drug use.</p> <p>The <u>contact</u> and social networking investigations directly linked this index case to five secondary cases. Two contacts to one of the secondary cases also developed active TB.</p> <p>Four cases were quite advanced when identified and appeared to have had extended periods of illness.</p> <p>Two of the patients in this outbreak made multiple visits to physicians before their TB was accurately diagnosed.</p>	
Response	
Programs Implemented	<p>CDC staff participated in Grand Rounds of key St. Louis area hospitals to educate physicians and emergency room staff.</p> <p>All of the MDR patients were housed at the Missouri Rehabilitation Center for at least part of their treatment. Some patients were under court order to remain at the facility for the duration of treatment.</p> <p>The New Jersey Medical School and the National Jewish Medical and Research Center provided consultation to the Missouri Rehabilitation Center staff, most of whom had limited TB experience.</p>
Program Outcomes	<p>Housing MDR patients at the Missouri Rehabilitation Center eliminated the risk of nonadherence to isolation and treatment.</p> <p>The medical staff at the Missouri Rehabilitation Center gained expertise and experience with state-of-the-art TB treatment and are now a statewide resource for MDR TB cases.</p> <p>To date, no reactivation of disease has occurred in these patients.</p> <p>Additional MDR cases linked to this outbreak are likely to occur due to the delay in diagnosis of several of these cases and the transient population with whom they had contact.</p>

Information on Your Program Area's At-Risk Populations

Better understanding the at-risk populations in your program area will help you to address stigma, as well as the language and cultural issues impacting your program area's TB prevention and control efforts. In addition, these at-risk populations are a source of valuable insights, leadership, and support.

What Information about an At-Risk Population Revealed: Cultural Differences Interfere with TB Prevention and Control	
Subject	Knowledge, Attitudes, Beliefs and Behaviors: Selected TB Information Associated with Patients from Somalia
Country of Origin	Somalia Source www.ethnoMed.org
Significant Findings	
<p>The extreme social isolation and stigma associated with TB in Somalia are at least as severe as those associated with AIDS in the United States.</p> <p>Diagnosis of TB has traditionally led to a lifetime of social isolation, stigma, and illness.</p> <p>Patients may deny sharing housing or may fail to provide names of contacts when they believe their TB diagnosis will be revealed to these contacts.</p> <p>Persons with severe symptoms may fail to seek medical care and deny their illness to themselves and others.</p>	
Response	
Recommendations to Providers	<p>Treat the diagnosis of TB with sensitivity and maintain strict confidentiality, similar to that of HIV diagnoses.</p> <p>Educate your patient about the curable nature of TB.</p> <p>Take time to discuss the social ramifications of the disease with the patient.</p>

At-risk population information can be divided into two parts: General background information, and information specific to your program area.

General Background Information

General background information can increase your awareness of and sensitivity to cultural issues. At the same time, be careful not to stereotype and assume that every individual will exhibit all characteristics of the larger group norms.

General background information includes

- Values and culture
- Health care priorities

- Factors influencing when and where medical attention is sought
- Knowledge, attitudes, beliefs, and behaviors associated with TB, illness, and medical treatment
- Fears and beliefs associated with receiving public health services and interacting with government agencies

Gathering this information is a critical first step toward partnering effectively with at-risk populations and those that serve them, and gathering it is much easier than it seems. Much of it can be obtained through an initial one-hour investment of your time on the Internet. Information that can be found on the Internet includes

- Social stigma associated with TB
- Common misconceptions associated with TB disease, skin-testing, and treatment
- Common acculturation issues faced by the population
- General etiquette
- Norms associated with touch and personal space
- Gender roles
- Family and kinship structure
- Religious beliefs and practices
- Community structure
- Traditional medical practices
- How the culture views and deals with illness
- How medical decisions are made and by whom
- How medical news is managed

At-Risk Population Findings

In Los Angeles County, information gathered from patients with active TB revealed that unemployment and not knowing where to obtain care were more closely associated with delays of treatment in excess of 60 days, than was severity of TB disease symptoms (*TB Notes* No. 2, 2001).

Among the sites on which information like this can be found is www.ethnomed.org. This site makes specific recommendations to health care providers and provides information about cultural beliefs and health-related issues.

Information Specific to Your Program Area

The following information will help you to access and work with your at-risk populations:

- Local population structures such as faith-based, cultural, and community organizations that are respected and have influence
- Gathering places, cultural events, and festivals

- Common sources of employment
- Respected influential leaders
- Primary care providers serving the population
- Respected community-based organizations serving the population
- Trusted communication channels, such as community newspapers, media outlets, organizational newsletters, and word of mouth

Leaders Provided Effective Strategy for Reaching At-Risk Populations

Stigma associated with TB and misinformation about the BCG vaccine kept Filipino-born patients from requesting TB services from their primary care physicians. Filipino leaders revealed that stigma made public forums, such as community meetings, a poor first choice for reaching this population. Instead, they recommended that newspaper articles providing TB information and encouraging individuals to seek services from their providers be placed in Filipino community newspapers. The leaders offered key messages addressing TB that were included in the articles.

To ensure your information is comprehensive and accurate, it is important to identify and speak directly with respected influential individuals from at-risk populations in your program area, not just those providing services to the population. Meeting with these leaders

- Helps you develop a deeper understanding of current assets, stigma, and issues that will impact your TB work;
- Creates an opportunity to develop trust and honest dialogue about effective strategies to address these issues and priorities; and

Working One on One

Some program areas have experienced positive results by working directly with individual clinics, hospitals, universities, and private practice physicians to provide them with epidemiological information and clinical training. Sample slide set presentations and training materials are available through the CDC at www.cdc.gov/tb.

- Establishes a communications link with a respected and influential member of your high-risk population.

One way to identify respected influential leaders is to ask people you know for suggestions, and then ask each suggested person for additional recommendations. If this sort of contact is not possible, a cold call (e.g., a contact—phone call, e-mail, or visit—made without prior introduction or interaction) to a religious organization or a service agency working with the population is likely to provide you with names to pursue.

In addition to meeting with leaders of at-risk populations, you may find that conducting one or more focus groups or discussion groups with members of at-risk communities will yield valuable information about the populations at risk in your program area.

The *At-Risk Population Information Worksheet* and information provided in Chapter 5: *Determining Your Purpose and Choosing Partners*, will help you to gather the information you need and to recruit effective partners from at-risk populations.

Understanding Primary Care Providers in Your Program Area

A comprehensive understanding of your TB environment includes information about the primary care providers (PCPs) serving your at-risk populations. Identify the emergency and non-emergency health care providers attending the majority of at-risk population members. Understand them by

- Evaluating their understanding of TB epidemiology and patient risk factors in your program area, as well as of screening and treatment protocols
- Assessing their willingness to work cooperatively with public health agencies
- Evaluating their cultural competency levels
- Identifying their perceived barriers to early diagnosis of TB and treatment completion
- Identifying individuals and organizations they respect

Associations of Health Care Professionals

Organizations of health care professionals are potential partners in reinforcing TB awareness by including TB on their agendas for specialty training and certification, and in conferences for continuing medical education. Many of your colleagues have identified and developed relationships with associations and networks of primary care providers, including regional or state hospital associations, medical societies, HMOs, associations of emergency department physicians, associations of infectious disease practitioners, and health clinic networks. The following organizations have been active in TB control on a national level and may have affiliates in your program area:

- American Academy of Pediatrics
- American College of Chest Physicians
- American College of Physicians-American Society of Family Medicine
- Migrant Clinicians' Network
- Infectious Diseases Society of America
- American Academy of Family Physicians
- National Health Care for the Homeless Society Council
- American Thoracic Society

Research indicates that as TB cases decline, PCPs become less aware of who their high-risk patients are and thus are less likely to consider TB in their differential diagnosis of at-risk patients. Meeting with PCPs to better understand their perceptions of TB is a first step toward raising TB awareness. These meetings can lead to

- Increased cooperation with, and support for, your TB program
- Sponsorship of TB education and training programs
- Consistent and ongoing information sharing about changing epidemiological trends

The *Associations of Primary Care Providers and Professional Associations Worksheet* can help you gather the information you need.

What a Survey of Health Care Providers Revealed: Addressing Primary Care Providers' Cultural Competencies in TB Control	
Subject	Identification of cross-cultural competency levels among outreach workers, public health nurses, and clinicians in Minnesota.
Location	Minnesota
Source	<i>TB Notes</i> No.3, 2002
Key Findings from a Statewide Survey	
<p>The cultural competency needs expressed by health-care professionals in urban and suburban areas differed significantly from those in rural areas.</p> <p>All providers wanted to improve their skills, knowledge, and expertise in communicating with culturally diverse patients and involving them in their own health-care decisions.</p> <p>Rural areas were more likely to work exclusively with Hispanic and Latino populations, while urban areas worked more with African and Southeast Asian TB clients.</p>	
Response	
Programs Implemented	Collaborated with the Minnesota-based Center for Cross-Cultural Health to present two half-day workshops titled "Cross-Cultural Issues in TB Prevention and Control in Minnesota." One workshop was designed to meet the needs of urban and suburban professionals. The other was designed to serve rural professionals and was simultaneously broadcast live to 11 videoconference sites around the state. The conference was videotaped and free copies are available.
Program Outcomes	Physicians, public health nurses, and outreach workers, as well as nurses from businesses employing large numbers of immigrants, attended both workshops.
	Additional collaboration opportunities are being explored with the Center for Cross-Cultural Health, including the possibility of including members of high-risk populations in future forums to share cultural information aimed at identifying and implementing mutually acceptable TB prevention and control strategies.

Comparing Your Data to Your Area's TB Program

Part of understanding your environment includes analyzing how closely your TB program goals, objectives, and resources are aligned with your epidemiological profile and your environment.

Your TB program analysis will help you to:

- Obtain data on program inputs (e.g., funding and equipment) and outputs (e.g., the percentage of patients completing therapy), and review your program goals and objectives.

- Analyze the TB program’s current results, comparing them with existing program goals and objectives and taking into consideration changing environmental trends.
- Recognize and delineate successes, as well as problem areas and gaps in services.
- Determine possible strategies for improving performance by building on strengths and competencies and by addressing problem areas.
- Estimate the additional resources and competencies needed to help implement those strategies and meet new program objectives.

Formation of the Kansas TB Control Coalition

The Kansas TB Control Program created a statewide TB coalition that includes public health entities, private providers, government entities, nonprofits, associations of medical professionals, religious groups serving at-risk populations, schools, the department of corrections, and a university. One of the many benefits was the Kansas Association for the Medically Underserved asking the TB Control Program to join forces with them to reach providers with TB education and information. (*TB Notes* No. 3, 2000)

Identifying and Understanding Additional Stakeholders

For the purposes of this guide, a TB stakeholder is any group or individual impacted by TB; thus, TB stakeholders have a stake in preventing and controlling the disease. In reality, everyone in society is a potential TB stakeholder. Our challenge is to awaken an interest in, and commitment to, TB prevention and control among more and more stakeholders. You can use the specific needs, opportunities, and issues identified in your epidemiological profile and your information on primary care providers, at-risk populations, and your program to prioritize your identification and recruitment of new TB stakeholders as partners (see Chapter 5: *Determining Your Purpose and Choosing Partners*). Information you will want to know about new stakeholders includes:

- The mission, vision, and values of the stakeholder group
- Membership characteristics, including geographic distribution of members
- Key organizational contacts
- Organizational structure and decisionmaking procedures
- Respected members and leaders
- Communications channels, such as newsletters, broadcast e-mail lists, and websites
- Current activities, including volunteer or service efforts
- Regional or annual gatherings

Much of this information is easily obtained from the stakeholder organization’s website. Additional information can be gathered through a phone conversation with staff, organizational brochures, and annual reports.

Following is a partial listing of TB stakeholder groups that are partnering with TB prevention and control programs around the nation:

- Cultural and ethnic organizations
- Refugee and immigration organizations
- Native American Nations and organizations
- Citizens or residents associations
- Business and trade associations
- Financial institutions
- Employers
- Public and private schools
- Media
- Clinics and HMOs
- Private health care providers
- Correctional facilities and probation officers advocacy groups
- Long-term residential facilities
- Substance abuse programs
- Shelters and low-income housing programs
- Professional societies
- Lung associations and other voluntary groups
- Schools of medicine, nursing, and public health
- HIV/AIDS service organizations
- Government health care providers, such as Indian Health Services and the Department of Veterans Affairs
- Immigration and border officials
- Faith-based organizations

To locate possible stakeholders groups in your program area, visit the CDC National Prevention Information Network (NPIN) Website (www.cdcnpin.org) and select “Search for: Organizations.” You will find descriptions of more than 19,000 national, state, and local organizations that provide resources and services related to HIV/AIDS, STDs, and TB. Services include case management, counseling and testing, prevention, education and outreach, health care, support services, housing assistance, and treatment.

Related Resources

Cultural and Linguistic Competence Tools and Resources

- *The Bureau of Primary Health Care (BPHC) of the Health Resources and Services Administration (HRSA)*
BPHC offers tools and resources addressing cultural competence that can be accessed at www.bphc.hrsa.gov/quality/Cultural.htm.
- *Center for Immigrant Health*
The mission of the Center for Immigrant Health is to facilitate the delivery of linguistically, culturally, and epidemiologically sensitive health care services to newcomer populations. Access their website at www.med.nyu.edu/cih/.
- *Cultural Competency Resource List*
This resource list was developed and is maintained by the Cultural Competency Subcommittee of the TB Education and Training Network (TB ETN). The list

contains names, contact information, and descriptions of over 75 organizations worldwide. A copy of the *Cultural Competency Resource List* is available by sending an e-mail to tbetn@cdc.gov or by visiting the TB Education and Training Resources Website at www.findtbresources.org.

- *Linguistic and cultural aspects of tuberculosis screening and management for refugees and immigrants*
This transcript of a talk presented at the International Union Against Tuberculosis and Lung Disease Conference in March 1996 discusses some strategies for managing TB treatment and prevention in a multicultural, multilingual setting. It reviews management strategies and frequent areas of miscommunication that require special attention, explores why translation and patient education is a complicated process, and describes a system for negotiating cultural differences. Access this talk at www.ethnomed.org/ethnomed/clin_topics/tb/tb.html
- *The National Center for Cultural Competence of the Georgetown University Center for Child and Human Development*
The center offers tools and resources associated with cultural and linguistic competence, including self-assessment checklists. The center can be accessed by calling 1-800-788-2066 or at www.georgetown.edu/research/gucdc/nccc/index.html.

TB Program Assessment and Training Resources

- *The Public Health Training Network (PHTN) of the Centers for Disease Control and Prevention*
PHTN is a distance learning system that takes training to the learner. The network uses a variety of instructional media, ranging from print-based to videotape and multimedia, to meet the training needs of the public health workforce nationwide. PHTN can be accessed at www2.cdc.gov/phtn.
- *The TB Education and Training Network (TB ETN) of the Centers for Disease Control and Prevention*
TB ETN was formed to bring TB professionals together to network, share resources, and build education and training skills. Currently, membership includes representatives from TB programs, correctional facilities, hospitals, nursing homes, federal agencies, universities, American Lung Associations, Regional Training and Medical Consultation Centers, and other U.S. and international organizations interested in TB education and training issues. Additional information about TB ETN can be accessed at www.cdc.gov/tb/TBETN.

Additional Publications

- TB-Related News and Journal Items Weekly Update (TB-Update). A compilation of TB-related articles published for the benefit and information of people interested in TB. To subscribe to the list, or to change your subscription options, visit: www.cdcnpin.org/scripts/subscribe.asp#journal.
- CDC. Progressing toward tuberculosis elimination in low-incidence areas of the United States: recommendations of the Advisory Council for the Elimination of Tuberculosis. *MMWR* 2002; 51 (No. RR-5).
www.cdc.gov/mmwr/preview/mmwrhtml/rr5105a1.htm
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- CDC. Division of Tuberculosis Elimination. *TB Elimination, Now Is the Time*. Atlanta, GA. www.cdc.gov/tb/pubs/nowisthetime/.
- CDC. Division of Tuberculosis Elimination. TB Facts for Health Care Workers. www.cdc.gov/tb/pubs/TBfacts_HealthWorkers/default.htm