Confronting a Hidden Disease

TB in Roma Communities

ROMA HEALTH PROJECT

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Confronting a Hidden Disease:
TB in Roma Communities

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World Lung Foundation

A Research Report
Prepared for the Roma Health Project

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Executive Summary

International agencies such as the World Bank,[1] the United Nations Development Program (UNDP),[2] and the Council of Europe[3] report that TB is more prevalent in Roma communities and that the Roma are more vulnerable to TB. However, no comprehensive document exists outlining the available data regarding the prevalence of TB in Roma communities, the factors that shape Roma vulnerability to TB, and the barriers to TB control in Roma communities. This literature review outlines available quantitative and qualitative data, as well as current governmental and nongovernmental activities to address TB in Roma communities and recommended areas for program expansion.

(1) Roma Health Status

Almost all academic and gray literature agrees on three points: (1) there is little data about Roma health status, (2) data that does exist suggests gross disparities between Roma populations and majority ethnicity populations, and (3) poor health among the Roma is closely tied to the fact that they are overrepresented in the ranks of the poor.

(2) TB in Central and Eastern Europe and the CIS

According to the most recent data from the World Health Organization (WHO), 80 percent of the TB cases in Europe are concentrated in 16 countries,[4] many of which have substantial Roma populations. TB treatment in Central and Eastern Europe and the Commonwealth of

Independent States (CIS) generally requires two months of hospitalization, followed by four months of out-patient treatment.

Europe's lack of progress in TB control is notable. Directly Observed Therapy Short-course—DOTS, the internationally recommended strategy for TB control—coverage is lowest among the world regions in Eastern Europe, as is TB case detection.[5] TB and HIV coinfection are not yet major concerns in Central and Eastern Europe, though HIV rates are expected to continue to rise.[6]

(3) TB in the Roma Community

Ministries of health in Eastern Europe generally do not collect ethnically disaggregated data. As a result, discerning TB prevalence rates among the Roma is difficult. Moreover, it is difficult to know to what extent TB rates among the Roma are shaped by poverty and to what extent by the particular marginalization Roma face. Published academic literature regarding TB incidence and prevalence includes documentation of slower rates of decline in active TB rates among Roma than among the non-Roma population in Slovakia,[7] a micro-epidemic of TB among Roma children in the Czech Republic in 1990,[8] a TB incidence significantly higher than the national average in two Roma communities in Romania in the 1990s,[9] and a TB prevalence rate more than 2.5 times higher than the national average in a Serbian Roma community.[10]

There is additional quantitative and anecdotal data showing lower treatment completion rates among Roma TB patients. Two international NGOs have also documented difficulties encountered by Roma patients in accessing TB diagnosis and care, including health care workers making inappropriate requests for payment or refusing to see Roma patients.[11]

(4) Barriers to Health Care Access and TB Control

Looking only at TB prevalence and treatment completion data is not sufficient to guide research and program design. Socioeconomic and health care system contexts must be analyzed.

Barriers to TB control among the poor

Roma are inordinately poor,[12] and the poor are more vulnerable to TB. To aid efforts to address poverty and TB, WHO has identified economic, health system, socio-cultural and geographic barriers.[13]

- *Economic barriers*

  Evidence from NGOs confirms that economic barriers have a particularly strong impact in limiting Roma access to TB services. Anecdotal and survey data collected by NGOs show that Roma may be more sensitive to cost concerns than TB patients of majority ethnicity.

- *Barriers posed by stigma*

  TB stigma could lead community members to avoid or shop around for a diagnosis and could impede treatment completion or even health education efforts. Stigma about women and TB may be qualitatively different from stigma relating to men infected with TB. No information was found about whether or not TB stigma is gender specific in the Roma community. However, it is known that as women and members of an excluded ethnic minority, Roma women face particular health system discrimination.[14] The role of health care workers in perpetuating TB stigma could be particularly pertinent when looking at the Roma, who may lack trust in health care systems that have sometimes excluded or mistreated them.

- *Knowledge barriers*

  Poor knowledge among the general public about TB disease and services is one cause of stigma. Low TB knowledge and health literacy may also result in failure to access TB testing or treatment. Individuals may not know that they are experiencing symptoms of a fatal disease or that the disease is treatable.

  A survey done in Romania showed significant discrepancies between Roma and majority ethnicity respondents in TB knowledge, including the fact that it is contagious and curable.[15]

- *Cultural barriers*

  Inadequate communication between patient and provider can delay diagnosis, result in poor treatment support and adherence, and erode overall trust in the health care system.[16] Communication may be poor when health providers are ignorant of a client's culture.

  Of the three articles relating to Roma culture and health that were considered for this review,[17] the most commonly cited elements of Roma culture pertinent to health service provision include traditions about cleanliness, the importance of the family in supporting the ill, the importance of eating home cooked food as a family, and practices at death. An NGO survey revealed that norms around family may be significant in whether or not a Roma individual seeks TB care.[18]

- *Geographic barriers*

  Roma often live far from primary health care centers, and even farther from sites that can provide TB diagnosis. Even in cases where they live only several kilometers away, they may be limited by lack of public transport, impassable roads, or the costs required to reach the health center.[19]

(5) Existing Interventions Addressing Higher Rates of TB among the Roma

Few countries comprehensively address TB among the Roma as part of their strategies to fight TB, although some Roma communities may be targeted as risk groups in TB (as well as HIV) projects. The Roma minority is addressed in some current Global Fund grants. International and national NGOs have undertaken some interventions to decrease TB among the Roma, but efforts are not nationwide and are for now focused primarily on data collection.

(6) Opportunities for Additional Interventions Addressing TB among the Roma and other Marginalized Populations

Extant models for TB control in vulnerable groups include the following:

A) Active case finding

Symptom-based case finding has been found to be cost effective in areas with undetected cases.[20] There is little data on case detection among the Roma, and indeed, on case detection in the region overall. However, the epidemiological and TB knowledge data cited above suggests that there are many undetected TB cases in Roma communities.

B) Patient support programs to ensure treatment completion

Treatment interruption contributes to the development of drug resistance, to TB transmission, and to poor outcomes for individual patients.[21] In a retrospective review of program results worldwide, programs with "enhanced Directly Observed Therapy," which consists of treatment observation, social support, incentives, and enablers, had the highest rates of success.[22]

Patients' clubs or support groups are one kind of social support. There is little documentation about the current number and effectiveness of TB patients' clubs or support groups, but they are often cited as a method of treatment completion support and patient empowerment.[23]

Some other innovative methods that have been used to assist treatment completion in middle- and high-income countries include case management and complementary social service referral in New York City;[24] the use of peer health advisors for homeless TB patients in San Francisco;[25] and increased supervision of TB program staff in Korea, leading to improved quality of care.[26]

C) Incentives for case detection and treatment completion

Incentives for case detection and treatment completion may be for care providers or for patients. Anecdotal and existing quantitative data from programs in Eastern Europe indicate that programs targeting patients substantially improve case detection and treatment completion. Programs targeting health care providers were also reportedly effective.

D) Advocacy and health communication

Most Central and Eastern European countries have reasonable infrastructure and medical expertise (although DOTS coverage may be low). Gaps exist instead in such areas as the national TB program's consideration of poverty, in the implementation of existing policy that TB treatment is free, in program planner and provider knowledge of TB in the Roma community, and in at-risk community knowledge of TB disease and services. With the exception of scattered health education efforts, very little has been done to address these gaps.

(7) Conclusions and Recommendations

General conclusions and recommendations

- Additional research is required on TB incidence, prevalence, and treatment adherence in Roma communities.
- The ethnic elements of Roma vulnerability to TB must be considered in both research and interventions. However, most TB-specific programming should target geographic areas and not ethnic groups.
- The gender elements of TB vulnerability, stigma, diagnostic delay, and treatment adherence should be assessed and incorporated into programmatic planning.
- Community level interventions should be paired with interventions to impact the functioning of the health system.
- Efforts to address TB must be linked with comprehensive efforts to improve overall access to health care.
- Roma should be involved in program design and implementation.
- Governmental and nongovernmental health programmers and researchers should include HIV and Roma vulnerability to HIV in their planned research and/or interventions.
- New programs should mitigate the impact of out-of-pocket payments on the poorest segments of the population.

- In-patient treatment
  - The health system should develop ways of accommodating practices relating to food and family presence, or, reconsider the necessity of two months of in-patient treatment.

- Case finding
  - Door to door TB education and symptomatic case finding may be effective in the highest prevalence settings.

- Patient support programs
  - National TB Programs and partner agencies should pursue scale-up of effective programs, including facility-based patient support, that have been implemented in the region. Moreover, they could explore the feasibility of implementing community-based interventions (such as TB patients' clubs) that have been implemented elsewhere in the world.
  - Studies from the region show that substance abuse,[27] homelessness,[28] alcoholism, unemployment, and past incarceration[29] are key determinants of challenges to treatment adherence. Strategies for TB patient support should endeavor to address these specific challenges among patients of all ethnic backgrounds.

- Incentives
  - Implementation of an incentives program in a region with high TB prevalence, low case detection, or low treatment adherence might remedy some limitations to TB diagnosis and treatment completion among Roma in the region, particularly given the seeming role of economic barriers in limiting Roma access to TB services.

- Advocacy and health communication
  - The paucity of data and programming highlights a need for advocacy to European and national level health policymakers.
  - Any bio-medical interventions to address TB among the Roma community should address political commitment gaps at all levels.
  - It is likely that health education could successfully improve knowledge and boost case detection.

Introduction

The 12 to 15 million members of the Roma minority living in Eastern and Western Europe experience entrenched marginalization in education, housing, politics, and the labor market. This marginalization is manifest in health status; Roma exhibit some of the worst morbidity and mortality indicators in the region. Heightened TB prevalence is one such indicator.

International agencies such as the World Bank,[30] the United Nations Development Program (UNDP),[31] and the Council of Europe[32] report that TB is more prevalent in Roma communities and that the Roma are more vulnerable to TB. National NGOs, advocates, and public health experts echo these concerns. However, no comprehensive document exists outlining the available data regarding the prevalence of TB in Roma communities, the factors that shape Roma vulnerability to TB, and the barriers to TB control in Roma communities.

Confronting a Hidden Disease: TB in Roma Communities outlines available quantitative and qualitative data, and goes a few steps further by outlining current governmental and nongovernmental activities to address TB in Roma communities and recommended areas for program expansion. The resulting document should inform national TB programs; ministries of health, social affairs, or minority integration; international agencies; and NGOs about academic and gray literature* currently available, as well as research needs and program opportunities.

Information from all of Europe and the Commonwealth of Independent States (CIS) is presented, but the review largely focuses on the countries of Central and Eastern Europe. This geographic focus on Central and Eastern Europe is due to the fact that countries in this region face significant challenges to health and social assistance coverage for all, and they generally have the highest percentages of Roma citizenry.

Methodology

The author consulted known sources of gray literature, conducted PubMed and Google searches, searched abstracts presented at the European Respiratory Society Annual Conferences from 2001–2006, searched abstracts presented at the International Union Against Tuberculosis and Lung Disease in 2006, and spoke with programmers working on Roma health and/or TB. Non-English language sources that are abstracted in English in PubMed were included (although the entire article was not read). French language searches were conducted in Google. Transcripts from roundtables and interviews conducted among Roma community health workers and their clients in Bulgaria, Finland, and Romania, were also consulted. These roundtables were held as part of an earlier study conducted by the author.

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* Gray Literature consists of publications issued by government, academia, nongovernmental organizations, international organizations, and business in both print and electronic formats, but not controlled by commercial publishing interests. In contrast, academic literature appears in peer-reviewed scholarly journals.

Literature addressing each of the following rubrics was reviewed: (1) Roma health status, (2) TB in Central and Eastern Europe and the CIS, (3) TB in the Roma community, (4) barriers to health care access and TB control, (5) existing interventions addressing higher rates of TB among the Roma, and, (6) opportunities for additional interventions addressing TB among Roma and other marginalized populations.

Confronting a Hidden Disease: TB in Roma Communities is not a standard academic literature review for three reasons. First, since much of the existing data collection and program planning has been undertaken by governmental or nongovernmental agencies and not by universities, the author examined more gray than academic literature. In fact, not all of the documents reviewed have been published or are available to the general public. Second, a robust discussion of Roma and TB required consideration of many cross-cutting issues. Given the number of such issues considered, it was not feasible to summarize all articles or books found relating to each rubric here. Every document found that addresses Roma and TB *per se* was read and reviewed, but only a representative sample of other documents are noted. Finally, in order to make the document useful to program planners, it is a program review as well as a literature review. Existing programs, challenges, and opportunities are discussed. The information presented is synthesized in a final recommendations and conclusions section in which explicit suggestions are made to policymakers, NGOs, and advocates.

Roma Health Status

Almost all academic and gray literature agrees on three points: (1) there is little data about Roma health status, (2) data that does exist suggests gross disparities between Roma populations and majority ethnicity populations, and (3) poor health among the Roma is closely tied to the fact that they are overrepresented in the ranks of the poor.

Two academic literature reviews on Roma health have been published since 2000. Their conclusions suggest that much of the research that has been conducted reflects biases of the data collectors. For example, one academic team noted that much of the existing literature focuses on infectious disease and reproductive health, indicating a prejudicial concern for the ways in which Roma health status can negatively impact majority populations rather than a concern for Roma health as such.[33] They found further that there was little data relating to Roma access to health services.[34] The second academic review pointed out that half of all articles reviewed examine the genetic characteristics of the Roma,[35] highlighting a general lack of analysis or attention to the social determinants of inferior Roma health status.

Statistics from major studies and reports show that the spotty health data that does exist is alarming. Ill health is more prevalent among the Roma than among surrounding populations. A 1997 study in the Czech Republic revealed large discrepancies between Roma and majority ethnicity populations in infection rates for a number of diseases.[36] Other stud-

ies have found higher rates of type two diabetes, coronary artery disease, and obesity among Roma adults,[37] and vitamin deficiencies, malnutrition, anemia, dystrophy, and rickets among children.[38] Roma women suffer from even more barriers to improved health status than their male counterparts,[39] as they face gender-based limitations to health rights within their own community, and ethnicity and gender-based limitations in the wider community.[40]

Overall ill health leads to earlier death. A comprehensive UNDP report on Roma poverty states that infant mortality rates in the Czech Republic, Slovakia, and Hungary are about twice as high among the Roma as among the non-Roma.[41] High rates of infant mortality are not confined to Eastern Europe; Irish Traveller communities also experience infant mortality rates twice that of settled populations.[42] In fact, a World Bank study that examined almost all available data on Roma mortality in Eastern Europe reported that life expectancy for Roma throughout Eastern Europe is about 10 years less than that of the overall population.[43]

Roma health is poorer in part because of lack of health care access. Local level data outlines the elements and extent of the underutilization of health services. An NGO survey in two Romanian regions revealed that 98 percent of poor Romanian respondents were registered with a general practitioner, as opposed to 48 percent of the Roma.[44] Bulgarian authorities report that nationally, between 3 and 7 percent of children have not been vaccinated, while NGOs report that as much as 14 percent of children in some Roma communities have not been revaccinated for poliomyelitis and diphtheria.[45] Macedonian advocates report that 30 percent of the Roma in Skopje's largest Roma community are uninsured, while 90 percent are uninsured in the smaller city of Stip, and about 100 percent are uninsured in isolated settlements.[46]

What limits Roma access to care? The most common obstacles listed in the above-cited literature reviews, the UNDP report, and a Council of Europe report on barriers to health care for Roma women included: poor communication between Roma patients and health providers, direct discrimination[47] by health providers and local authorities, indirect discrimination[48] by the health care system, health system failure to make general health information or health service information accessible to the Roma community, and geographic distance between Roma communities and health care facilities. Additional obstacles existing in the Roma community included: low levels of literacy and health awareness, inability to cover health care related costs, and lack of documentation necessary to obtain health insurance.

TB in Central and Eastern Europe and the CIS

According to the most recent data from WHO, 80 percent of the TB cases in Europe are concentrated in 16 countries,[49] many of which have substantial Roma populations. These countries include all of the countries in the Commonwealth of Independent States, the Baltic Republics,

and Romania.[50] Prevalence, which is usually expressed as the number of TB cases per 100,000 population, is also fairly high in other Eastern European countries. National TB programs reported the following prevalence rates to WHO: 36/100,000 in Bulgaria, 66/100,000 in Croatia, 210/100,000 in Moldova, 50/100,000 in Serbia and Montenegro, and 34/100,000 in Macedonia.[51] Persons consulted in the writing of this review suggested that some of these rates may reflect substantial under-reporting.[52]

While Central and Eastern Europe trail other regions, such as sub-Saharan Africa, in prevalence rates, Europe's lack of progress in TB control is notable. Directly Observed Therapy Shortcourse (DOTS)—the internationally recommended strategy for TB control—coverage is lowest among the world regions in Eastern Europe, as is TB case detection.[53] WHO reports that the rates of multidrug resistant TB in Central and Eastern Europe and the CIS are among the highest in the world. Data from the countries comprising what WHO designates as the European Region (Western, Central, and Eastern Europe; and the Commonwealth of Independent States) reveal the highest rate of treatment failure in the world (7 percent), and the second-highest rate of death as a treatment outcome (6 percent).[54]

TB and HIV coinfection is not yet a big problem in Eastern Europe, with the HIV-positive accounting for less than 0.05 percent of new adult TB cases in several countries.[55] However, the few countries with more advanced HIV epidemics, such as Ukraine, have higher rates of coinfection. HIV-positive persons account for 8.3 percent of new TB cases in Ukraine.[56]

TB treatment in Central and Eastern Europe and the CIS generally requires two months of hospitalization, followed by four months of out-patient treatment. This is unusual when considering treatment standards in other countries. For example, in the United States and the United Kingdom, hospitalization is not initiated as a matter of course, but based on clinical indications, patient homelessness, or a decision by a health care worker that it is required to ensure adherence. It is usually for a period shorter than two months.[57] Other countries, such as Italy, have higher hospitalization rates, but even then, hospitalization is certainly not routine nationally.[58] Indeed, the Technical Review Panel of the Global Fund to Fight AIDS, Tuberculosis, and Malaria has criticized an "inappropriate focus" on in-patient treatment in TB control in the region.[59] Studies on TB care in Russia concluded that hospitalization for TB was overused, draining resources and substituting hospital care for needed community-based social services.[60]

In the case of multidrug resistant TB, treatment takes longer than six months. The exact duration depends on the extent of drug resistance.

TB in the Roma Community

Quantitative Epidemiological Data

Ministries of health in Eastern Europe generally do not collect ethnically disaggregated data. As a result, discerning TB prevalence rates among the Roma is difficult. Many gray and academic literature publications refer to heightened vulnerability to TB among the Roma, but few provide concrete numbers. The publications that do provide statistics refer to the same few studies.

Moreover, it is difficult to know to what extent TB rates among the Roma are shaped by poverty and to what extent by the particular marginalization Roma face. Research conducted among other marginalized ethnic groups suggests that being a member of a minority ethnic group can be an independent risk factor for TB infection. In other words, being poor puts one at risk, but being poor and an ethnic minority makes one more vulnerable to TB. For example, a researcher from the Harvard School of Public Health asserted that residential segregation in the United States may *indirectly* affect TB transmission via the related decline in social cohesion and distance from health services. Isolation and cramped living may *directly* contribute to TB transmission,[61] as the TB bacillus spreads from person to person more easily in small and crowded homes. Another study done by the Centers for Disease Control found that socioeconomic deprivation alone was not enough to account for elevated rates of TB among ethnic minorities in the United States.[62]

In general, Roma are different from poor people of the majority ethnicity population in that they are more likely to remain poor,[63] often live in ghettoized settlements of cramped housing that are far from health services,[64] and routinely experience discrimination from the health care system and other state services.[65] Given this, it is safe to assume that as an ethnic group, they are especially vulnerable to TB. Existing data bears this out.

Published academic literature regarding TB incidence and prevalence includes the following:

- A study examining TB in western Slovakia from 1963 to 1967 found that active pulmonary TB fell more slowly among Roma than among other Slovaks.[66]

- Researchers from the Czech Republic note that there was a micro-epidemic of TB among Roma children in the Czech Republic in 1990.[67]

- A retrospective study of the Romanian town of Ciurea revealed that tuberculosis incidence (the number of new cases per 100,000) in 1995 was 1378.6 /100,000 among the Roma, more than seven times higher than among the non-Roma. In 1996 it was 2.1 times higher, and, while it significantly decreased in 1998 and 1990, it increased again in 2000 by over 2.3 times.[68]

- Researchers in Romania report that in 2000, countrywide TB incidence was 112.4/100,000, as opposed to 163.9/100,000 in Bucharest's Sector V, a neighborhood that is primarily Roma.[69]

- Active case finding carried out in a Serbian Roma community revealed an active pulmonary TB prevalence rate of 176.9/100,000 among the approximately 4,000 who agreed to screening.[70] Serbia reported to WHO that the 2000 prevalence rate in all of Serbia was 65/100,000.[71]

Searching Pubmed and Google and looking at references for the two largest regional assessments of Roma poverty—undertaken by the UNDP and the World Bank—revealed no other prevalence statistics. TB prevalence research that is planned as part of Global Fund activities in Serbia and Macedonia should provide additional information.

The Ethnic Minorities Health Problems Foundation (EMHPF), a Bulgarian NGO, has gathered and published some of its own research on TB prevalence among the Roma communities in Senovo, Kyustendil, and Tulovo, Bulgaria. The rates were 600/100,000, 1800/100,000, and 1600/100,000 respectively. In 2004, Bulgaria reported to WHO that its overall TB prevalence rate was 36/100,000.[72] About one quarter of the cases in Senovo, Kyustendil, and Tulovo were pediatric. The publication additionally states that the City Phthisiastric Hospital in Sofia reports that 30 percent of those receiving in-patient TB treatment are Roma and a specialized hospital for pulmonary disease in Sliven told the EMHPF that 60 percent of their patients are Roma.[73] Precise figures are not available, but it is known that Roma comprise a much smaller percentage of Bulgaria's population. Estimates range from 600,000 to 1 million[74] out of a total population of about 7.5 million.[75]

It appears that TB prevalence is generally higher in Roma communities, although the data is not ample enough to draw broad conclusions. The following additional quantitative and anecdotal data shows lower treatment completion rates among Roma TB patients:

- A British medical student who had worked in Bucharest reported to the *Student British Medical Journal* that he noted high rates of TB among the Roma, due in part to their failure to complete treatment.[76]

- Focus groups conducted among Romanian health providers and public health staff confirmed that Roma patients have lower rates of TB treatment completion. Focus group participants in Transylvania told a visiting academic team that Roma disproportionately failed to adhere to suggested treatment, and that they sometimes left the hospital in the middle of the intensive phase of DOTS.[77]

- The Romanian Institute of Pulmonology analyzed 126 Roma who had been registered as TB patients in 1996 and 1997. Of these, only 48 percent success-

fully completed chemotherapy and were cured. The institute explained this poor result as being due in part to the high percentage who suffered from related illnesses—66.7

- Doctors of the World (DOW) reports that Roma health mediators[79] state that Roma patients disproportionately discontinued the intensive phase of TB treatment and left hospitals due in part to persistent requests from medical staff to make supplementary (and illegal) payments.[80]

- Researchers in Plovdiv, Bulgaria, followed all MDR-TB cases from 1999 to 2004. Seventy-eight percent of the cases of treatment failure were Roma.[81]

DOW and the European Roma Rights Centre (ERRC) have also documented difficulties encountered by Roma patients in accessing TB diagnosis and care. A sputum smear is the most important element of pulmonary TB diagnosis. Roma Health Mediators in Romania reported that, when they were not present, Roma clients seeking a sputum smear were asked to pay. It is not known if these payments are requested from ethnic Romanian clients, but they are contrary to policy and likely constitute an obstacle for all poor patients. They also reported that, in several different counties, Roma were turned away from diagnostic services. In one case, the presiding physician explained that "extra work" would be required to treat the expected high number of Roma that would be sputum smear positive, and to trace the expected high percentage of these that would default.[82] ERRC identified a woman in Skopje, Macedonia, who, along with her two children, had been diagnosed with TB four months prior, but who had been denied treatment because it was not clear to the physician if her health insurance was valid.[83]

Barriers to Health Care Access and TB Control

Looking only at TB prevalence and treatment completion data is not sufficient to guide research and program design. Socioeconomic, Roma community, and health care system contexts must be analyzed. Links between TB and poverty are well established, as are the key roles played by TB knowledge and stigma,[84] and social and geographic factors in shaping TB epidemiology.[85] Looking at existing information on the Roma and poverty as well as barriers to TB control in Roma communities helps us to draw further conclusions on TB in the Roma community.

Roma and Poverty

Roma are poorer than other groups and are more likely to fall into poverty.[86] NGO studies reveal a troubling picture of poverty's impact on Roma living conditions and health. The European Centre of Minority Issues (ECMI), for example, conducted a random survey of 400 Roma families in 10 Macedonian cities, and 49.5 percent of those surveyed ate dough-based meals two to three times per week. Sixty-nine percent shared a space of between 10 and 15 square meters with 5 or 6 other inhabitants.[87] ECMI also conducted research in Serbian communities, reporting that Roma cited unemployment and living conditions as leading to stress and alcohol abuse, as well as to violence against women and children.[88] Intergovernmental agencies report how these local level conditions are not confined to particularly unlucky communities, but prevail at the national level. The World Bank reports that in 1997, 84.3 percent of Bulgaria's Roma were poor. Similarly, in 1997 in Romania, 78.8 percent of the Roma lived below the poverty line.[89] Even in Hungary, one of the wealthiest new EU members, 40 percent of Roma live below the poverty line.[90]

Not only do high percentages of the Roma live below the poverty line, they are concentrated among the most poor. A study of health insurance and equity in Bulgaria found that since 1990, there has been a substantial increase in the health care spending differences between the Roma and the rest of the population. According to the study's author, this increase resulted in part from the growing impoverishment of many Roma.[91] Data supports this assertion. When multiple levels of poverty were established among groups surveyed in Bulgaria, Hungary, and Romania, Roma were increasingly represented in the poorest groups.[92] In other words, Roma living below the poverty line may generally be poorer than majority ethnicity persons living below the line.

Poverty among the Roma is directly related to the discrimination they experience. For example, a 2006 European Monitoring Centre on Racism and Xenophobia report states that Roma face direct and systemic discrimination in education in EU countries.[93] Other European agencies and researchers have found links between discrimination and unemployment,[94] low health care access,[95] and poor housing.[96] The Council of Europe has explicitly acknowledged the role discrimination plays in limiting Roma access to health care, and has outlined how member states should address the causes and consequences in its standards document, *Recommendations to Member States on Better Access to Health Care for Roma and Travellers in Europe*.[97]

Barriers to TB Control Among the Poor

Roma are inordinately poor, and the poor are more vulnerable to TB. What are the particular challenges to TB control among the poor?

The World Health Organization (WHO), EQUI-TB at the Liverpool School of Tropical Medicine, and an academic team reviewing TB vulnerability in the publication, *Lancet*

Infectious Diseases, have identified barriers at several levels. The teams have given the barriers different names, but the content of these barriers was quite similar.

WHO cited *economic* barriers in the form of user fees, costs of transport to health centers, lost income/time, health care worker demands for out of pocket payments, and the purchase of ineffective drugs prior to diagnosis. *Health system* barriers included health service decentralization and its impact on resource allocation, and lack of health system responsiveness, which might include staff perpetuating TB stigma, poor communication skills among health care workers, inconvenient clinic hours, and unwillingness to work with particular patients. *Sociocultural* and *geographic* were the other two major types of obstacles found, with sociocultural barriers being linguistic and educational differences between patient and provider, among others, and geographic barriers being distance and road quality.[98]

The barriers found to be most pertinent to Roma are discussed below. In many cases, the data is thin, highlighting a need for additional research.

Economic barriers

Inability to cover imagined or real costs associated with TB diagnosis and treatment can lead one to interrupt treatment, or avoid diagnosis altogether. Evidence from DOW and EMHPF confirms that economic concerns limit Roma access to TB services. In interviewing TB patients, EMHPF repeatedly heard about the problems posed by the cost of travel to pick up drugs once diagnosis is confirmed.[99] Community health staff trained by DOW noted an absolute inability among many Roma to pay for any costs associated with TB, especially in systems whereby TB drugs were picked up daily.[100]

A Knowledge, Attitudes, Behaviors, and Practices (KABP) survey conducted by DOW among poor communities in Romania revealed the different impacts of economic concerns on the behavior of Roma and majority ethnicity respondents. Sixty-eight percent of the Roma stated that they would go to a doctor if they had a cough for more than three weeks, compared to 96 percent of poor Romanians from the majority population. Forty-seven percent of Roma stated that they would not go to the doctor because of concerns about cost, as compared to 22 percent of poor Romanians. The results were particularly notable in that all respondents were poor.[101] Differences in cost sensitivity might be explained by the fact that, taking all who live below the poverty line, Roma are concentrated in the bottom socioeconomic strata. In other words, the "poor Roma" surveyed are likely to be poorer than the "poor ethnic Romanians" surveyed.

Barriers posed by stigma

WHO cites stigma in its analysis of health system *and* sociocultural barriers to TB control, meaning that stigma can be perpetuated by health workers as well as by community members. TB stigma could cause persons experiencing TB symptoms to avoid or shop around for a diagnosis, or it could impede treatment completion or even health education efforts.

Stigma may be qualitatively different depending on the gender of the person believed to have TB. For example, women may be considered unmarriageable if they or a family member has suffered from TB.[102] Women and TB stigma is an under explored area, but stigma's disproportionate impact on women may influence mortality. Gender-based differences in health care access as well as fear of stigma may explain gender differences in case detection rates in some places.[103] The WHO reports that while more men are diagnosed with TB than women, a greater percentage of women die of it.[104]

There is little data specific to TB stigma relating to men or women in Roma communities. Roma health educators in Romania however, say that it exists and impacts individual behavior. Health educators noted that they were asked not to discuss TB when they brought it up with some community members,[105] as TB is a taboo topic.

TB stigma might be perpetuated at the health system level as well. Data from other settings suggests that health care workers can be key (and particularly damaging) purveyors of TB stigma.[106] The role of health care workers in spreading TB stigma could be particularly pertinent when looking at the Roma, who may lack trust in health care systems that have sometimes excluded or mistreated them. Roma women may be especially vulnerable to poor health system treatment, as they face particular health system discrimination.[107] In some cases, public health system staff have seriously violated the rights of their Roma women patients. Feared and stigmatized for their purported role in spreading infectious disease and in having "too many" children, Roma women have been subjected to forced sterilization[108] and segregated maternity wards,[109] among other indignities.

There is little data to buttress the thesis that health care workers perpetuate TB stigma when they are addressing Roma (or any other) clients. This is not because there is evidence to the contrary, but because little research has been done. This may be due in part to the difficulties inherent in assessing stigma among health care workers. Health care workers (and national TB programs) may not be eager to participate in a study assessing stigma among themselves, and even if they agreed, they would likely act differently while observed.

Knowledge barriers

WHO explains that poor knowledge on the part of providers can lead to health system barriers to TB diagnosis and treatment.[110] Health provider knowledge barriers might include inadequate knowledge of TB diagnosis and treatment protocols, means of treatment adherence support, or Roma culture. It does not appear that there has been any research to assess knowledge barriers among health providers.

Poor knowledge among at-risk communities can contribute to sociocultural barriers, such as stigma. Knowledge gaps may also lead to failure to access TB testing or treatment, as individuals do not know that they are experiencing symptoms of a fatal disease, or, if they do know this, they may not know that the disease is curable. Diagnostic delay due to poor TB knowledge has epidemiological repercussions; one study in the United States found that

between symptom onset and diagnosis, a patient exposes eight contacts, on average.[111] Another study in the United States found that 23 percent of household contacts of an untreated person with active pulmonary TB became infected within one to two months.[112] Twenty-four percent of an office staff team was infected in Australia, likely due to delays in TB diagnosis of two staff members.[113]

There has been limited research assessing knowledge in the Roma community.

The DOW KABP survey done in Romania showed discrepancies between Roma and majority ethnicity respondents in TB knowledge.[114] Again, respondents of both Roma and Romanian ethnicity were classified as poor.

	Ethnic Romanian	***Roma***
Have heard of TB	88%	60%
Of these, know TB is a lung disease	56%	34%
Of these, know TB is contagious	73%	50%

Of the Roma who knew that TB is contagious, 35 percent said that it could be spread by sharing utensils, by eating food prepared by someone with TB, by blood, or by touch. A further 16 percent provided no answer to a question about transmission. Of the Roma who have heard of TB, 50 percent think it can be treated, as compared to 81 percent of poor ethnic Romanians.

Cultural barriers

Inadequate communication between patient and provider can delay diagnosis, result in poor treatment support and adherence, and erode overall trust in the health care system.[115] The fact that health care workers are almost never Roma may contribute to poor communication. Having few health care workers from a marginalized group is believed to possibly perpetuate low health care access for possible TB patients. The U.S. Centers for Disease Control's (CDC) Advisory Council for the Elimination of Tuberculosis recommends that the sociodemographic composition of the community being served is represented in the composition of TB control program staff.[116] Qualitative data suggests that this assertion holds for the Roma community as well. In focus groups, poor Roma patients in Bulgaria and Romania explained that they feel more comfortable in sharing personal health information and questions with members of their own community.[117]

Given that currently there are so few Roma health care professionals, how can health care providers lessen the communication gap? Several articles attempting to describe Roma culture insofar as it is pertinent to health care provision were studied for this review. It is important to note that some Roma rights advocates say that this "culture" argument may

reflect a majority ethnicity tendency to classify the Roma community as being uncivilized and deficient, and thus responsible for their own predicament. However, articles studied were in publications targeting health professionals, and they seek to help providers to better serve Roma clients. The ostensible purpose was thus to improve the quality of health care services to the Roma, rather than to blame the Roma for their inferior health status.

Existing articles tend to generalize about Roma culture and rarely differentiate between different linguistic, religious, geographic, or national communities or social class. Of the three closely considered for this review,[118] the most commonly cited elements of Roma culture pertinent to health service provision include traditions about cleanliness, the importance of the family in supporting the ill, the importance of eating home cooked food as a family, and practices at death. Some mention socioeconomic issues, such as poor diet and lack of understanding about the importance of prevention, but it is likely that this is a misattribution of behaviors to culture rather than to poverty.

The DOW KABP survey revealed that norms around family may be significant in determining whether or not a Roma individual seeks TB care. Eighteen percent of the Roma surveyed stated that they would not seek diagnosis if they knew that treatment required two months of hospitalization. Eleven percent of ethnic Romanians would avoid diagnosis for this reason. Most Roma stated that they wanted to avoid hospitalization due to family obligations.[119]

Geographic barriers

Roma often live far from primary health care centers, and even farther from sites that can provide a sputum smear examination. Even in cases where they live only several kilometers away, they may be limited by lack of public transport, impassable roads, or the costs required to reach the health center.[120] Some Roma settlements have their own clinics, but these are often under-resourced, so travel to another facility is required for a need such as TB diagnosis and treatment.[121]

Some Roma rights advocates have argued that this lack of coverage is discriminatory.[122] It is unclear if health resource allocation is indeed ethnically motivated, or if inadequate health system coverage results from the fact that Roma live in overall poorer regions on the outskirts of urban areas or in isolated rural locales. Nonetheless, the need to travel longer distances to health facilities appears to disproportionately affect Roma. A survey carried out by the Hungarian Delphoi Consulting Company, for example, found that, excluding Budapest, 5.9 percent of the country's population lives in an area without a local general practitioner. In contrast, again excluding Budapest, 18.6 percent of the country's Roma population lives in an area without a local general practitioner. In Roma settlements that technically do enjoy general practitioner coverage, the practitioner may be present for as few as two hours per week.[123]

Existing Interventions Addressing Higher Rates of TB among the Roma

Despite gaps in our knowledge, the preceding information suggests that, due to poverty and other barriers, Roma are especially vulnerable to TB. How have governments, health care providers, NGOs, and advocates addressed this?

Few countries comprehensively address TB among the Roma as part of their strategies to fight TB, although some Roma communities may be targeted as risk groups in TB (as well as HIV) projects.

However, high prevalence rates of TB among the Roma community are cited in some country strategies for minority integration or for health reform, and the Roma minority is addressed in some current Global Fund grants. International and national NGOs have undertaken some interventions to decrease TB among the Roma, but efforts are not nationwide and are for now focused primarily on data collection that should inform future activities.

The following table summarizes Global Fund activities specific to TB:

Country	*Implementer*	*Activities*
Romania (four pilot counties and Bucharest)	Romani CRISS (national NGO)	• Health education • Training of Roma health mediators in TB and Directly Observed Therapy (DOT) • Disseminate Roma health and TB information to local health authorities and encourage collaboration[124]
Serbia (six cities with total Roma population of about 32,000)	Red Cross	• Case finding (PPD testing for children under 14; door to door symptomatic case finding and referrals for adults) • Health education • Incentive food parcel distribution[125]
Macedonia (5,000 Roma targeted)	Ministry of Health	• Active case finding through x-ray screening • Pilot food and transport incentives program for 200 vulnerable patients (will likely include Roma)[126]

Some of these activities address vulnerability, rather than risk-group status. The Macedonian incentives program, for example, is available to any patient who is vulnerable to default. Roma may be over-represented in this group, but ethnicity is not a determining factor in eligibility. Global Fund activity impact information is not yet available.

NGO activities outside of the Global Fund framework include a TB education and treatment support program undertaken by DOW, and data collection undertaken by the EMHPF in Bulgaria. DOW's project has consisted primarily of (1) training peer health educators and Roma health mediators in TB awareness and in Directly Observed Therapy (DOT), (2) support-

ing Roma health educators and mediators to implement a TB health promotion campaign, (3) training and supporting health educators to carry out small advocacy projects. DOW has noted particular difficulty in garnering the cooperation of many health providers and authorities, which has hindered program performance.[127]

Due to the long time frame required for impacting TB prevalence rates and to the lack of an ethnically disaggregated baseline, DOW does not have community-wide impact information. However, preliminary data suggests that health education is improving TB knowledge and is likely aiding case finding. The peer health educators conducted TB education sessions with 11,530 Roma, leading to 607 sputum smear examinations, and the detection of 49 TB cases. From these 49 cases, 464 contacts were referred. There is no data on TB prevalence among these contacts.[128] An endline KABP survey conducted in project areas showed improvements in TB knowledge. The percentage knowing that TB can be treated increased from 50 percent to 94 percent; the percentage stating without prompting that persistent cough is a symptom increased from 35 percent to 52 percent; and the percentage stating that, if diagnosed, they would take prescribed medicines increased from 63 percent to 99 percent.[129]

The literature search, enquiries to national TB programs, and conversations with NGO staff addressing Roma and TB revealed no other interventions other than those summarized above.

Opportunities for Additional Interventions Addressing TB among Roma and Other Marginalized Populations

The current interventions noted above as well as some of the extant models for TB control in excluded communities can be categorized in the following way: (1) active case finding, (2) patient support programs, (3) incentives for case detection and treatment completion, (4) advocacy and health communication. A brief discussion of the methods and evidence as well as regional experiences for each of these interventions follows:

(1) Active Case Finding

A recent literature review analyzes best practices and future prospects for active case finding. The review explained that active case finding efficacy is influenced by prevalence, epidemiological importance (infectiousness and number of contacts), the likelihood of being detected otherwise, and, cost.[130]

Active case detection may be conducted in a variety of ways. X-ray screening has been a common method in the past, but it is currently used much less frequently due to cost and

the requirement that patients travel to a health facility or that an x-ray machine be brought to the site.

The review concluded that surveying community members and focusing on three or more weeks of cough as a determining symptom provides a reasonable balance between sensitivity and specificity. Surveying out-patients at a hospital is a low cost method of symptoms-based case finding. However, this limits detection to patients who live in close proximity to a hospital and who also *access* the hospital.[131] This method may not be suitable for the most vulnerable Roma communities.

There is little data on case detection among the Roma, and indeed, on case detection in the region overall. However, the epidemiological and TB knowledge data cited above suggests that there are many undetected TB cases in Roma communities.

There are two known completed active case detection programs in Roma communities, and both were done in Serbia using x-ray screening. One was carried out in a Roma settlement in Vojvodina, identifying seven cases of active pulmonary TB out of a total of 3,958 Roma who consented to x-ray screening.[132] The second was carried out in a Roma settlement in Belgrade. One hundred and sixty-seven individuals voluntarily presented at a health facility for x-ray screening, and no cases of active or latent TB were identified.[133] The total population targeted for screening is not known. This second finding highlights the fact that screening should only be done in high prevalence communities, and that x-ray screening may not reach those who are most vulnerable. Community members were asked to travel to a nearby health facility for screening, so presumably many did not present.

(2) Patient Support Programs to Ensure Treatment Completion

Increasing case detection alone is not enough to control TB; treatment adherence is also key. Treatment interruption contributes to the development of drug resistance, to TB transmission, and to poor outcomes for individual patients.[134] The recently released International Standards of TB Control specify that, in part to ensure treatment adherence, "a patient-centered approach to administration of drug treatment, based on the patients' needs and mutual respect between the patient and the provider, should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services."[135]

Currently, there are a number of models for intervention and patient support to ensure treatment adherence. DOT entails someone watching TB patients take their medicine. It has been implemented in some form in many parts of the world, including in several places in Eastern Europe. DOT, which has generated substantial debate and controversy,[136] may be carried out by facility-based health care workers, community-based health care workers, NGO or community volunteers, and family members. In a retrospective review of program results worldwide, programs with "enhanced DOT," which consists of treatment observation, social support, incentives, and enablers, had the highest rates of success.[137]

Patients' clubs or support groups are one kind of social support. There is little documentation about the current number and effectiveness of TB patients' clubs or support groups, but they are often cited as a method of treatment completion support and patient empowerment.[138] Some groups are facility based. For example, Project Hope in Tajikistan implements a project whereby patronage nurses visit patients and their families, providing counseling, health information, and psychological support. Initial results from the project suggest it will lead to decreased rates of treatment default, with 41 of 44 patients who had previously defaulted completing treatment once the support groups were initiated.[139]

There are no known documented examples of community-based TB clubs in Europe or the CIS. The best documented example is in Ethiopia. The program was undertaken in light of poor treatment adherence, inadequate recording, little community education and awareness, and pervasive TB stigma. Patient members go as a group to DOTS centers, meet regularly to support one another and share information, and cooperate with community health workers in staging community theater and other innovative forms of TB awareness raising. Following treatment completion, recovered patients are encouraged to join locally organized anti-TB associations.[140]

Quantitative and qualitative evaluation suggests that these clubs are effective in increasing treatment completion and overall health literacy, decreasing TB stigma in the community, and identifying additional TB cases.[141] Indeed, a cohort study showed that 68.7 percent of those in the Ethiopian club completed treatment, as compared to 46.8 percent of those in a nearby district with no clubs.[142]

Some other innovative methods that have been used to assist treatment completion in middle- and high-income countries include case management and complementary social service referral in New York City;[143] the use of peer health advisors for homeless TB patients in San Francisco;[144] and increased supervision of TB program staff in Korea, leading to improved quality of care.[145]

(3) Incentives for Case Detection and Treatment Completion

Incentives for case detection and treatment completion may be for care providers or for patients. The underlying assumption is that incentives will provide additional motivation to public health and other staff/volunteers engaged in active case finding and treatment support, and will remedy financial and other obstacles to diagnosis and treatment adherence among TB patients. Incentives for providers have included gift certificates, fuel for vehicles, food baskets, awards and other types of recognition, and payment for cases detected or patients completing treatment.[146] Incentives for patients have included all of the above, as well as food for the patients' entire family, second-hand clothing, transportation vouchers, nutritional supplements, social service referrals, grocery store coupons, and hygiene products.[147]

Assessing the effectiveness of such programs is difficult, particularly because they are often paired with other interventions, making attribution of causality problematic. Moreover, provision of incentives generally requires greater contact with health or social care providers, so this contact, rather than the incentives as such, could affect treatment adherence. Many implementers have also not conducted impact evaluations. However, anecdotal and existing quantitative data from programs in Eastern Europe indicate that such programs may substantially improve case detection and treatment completion. Management Sciences for Health, an international NGO, conducted a literature and program review of such efforts, and highlighted the following results:

- A program led by the Czech Ministry of Health gave vouchers for purchasing goods to vulnerable persons if they agreed to a TB test and were found infected. Case detection increased five times among the homeless population.

- The NGO Merlin and the World Food Program created a comprehensive incentives program in Georgia targeting TB patients. Treatment default reportedly dropped from 35 percent to 0 percent.

- The Moldovan government and the Red Cross designed a food and hygiene package program that apparently increased treatment success of new sputum smear positive patients from 61.9 percent to 68 percent.

- When a Romanian national TB program transport vouchers initiative ended, treatment adherence dropped from 95 percent to 80 percent.[148]

The NGO Project Hope reported on its own program in Tajikistan, where 88 percent of sputum smear positive patients receiving food supplements completed treatment, as opposed to 63 percent of those not receiving supplements. Two percent of those receiving the incentives died, while 11 percent of the patients not receiving supplements died. Project Hope reported that coordination of incentive distribution with patient education efforts was key.[149]

Programs targeting health care providers were also reportedly effective. However, since these programs are always combined with incentives for patients, impact evaluation is not possible. In general, such efforts were found to increase provider willingness to undertake defaulter tracing and patient support.[150]

(4) Advocacy and Health Communication

Graphically, a broad conception of health communications and advocacy addressing TB and the Roma might look like the following:

Advocacy & Communication Target	*Policy*	*Policy implementation*	*Commitment*	*Increased resource allocation*	*Integration of TB with HIV, primary health care, and social assistance strategies*	*Increased knowledge of TB & Roma (TB disease, current situation, research needs)*
National government (including Ministry of Finance and political leaders)	X		X	X	X	X
MoH	X	X	X	X	X	X
NTP	X	X	X	X	X	X
Local policy-makers	X	X	X	X	X	X
Community			X	X	X	XX
Household/patient level			XX	XX		XX

X = possible point of entry, but not currently undertaken on a wide scale
XX = activities currently undertaken by at least one national TB program (NTP) or NGO

The table above illustrates current activities, as well as potential points of entry for advocacy or health communication activities. For example, the "x" in the "increased resource allocation" and "national government" box means that there is no known effort to advocate vis-à-vis national governments for greater funding or human resource dedication to TB in Roma communities.

In this framework, planners and advocates may aim to increase knowledge or commitment or to foster policy or practice changes at all levels. This framework is especially appropriate for looking at countries where absolute governmental resource deprivation is not a significant obstacle to TB control. Most European and CIS countries have reasonable infrastructure and medical expertise (although DOTS coverage may be low). Gaps exist instead in such areas as the national TB program's consideration of poverty, in the implementation of existing policy that TB treatment is free, and in program planner and provider knowledge of TB in excluded communities. Advocacy and education at many levels can remedy these gaps.

Failure to ensure that existing national TB programs reach the most vulnerable is a Europe-wide problem. Indeed, a recent *British Medical Journal* editorial called for greater attention to social exclusion when addressing TB in Europe,[151] and a *European Respiratory Journal* editorial cited increased poverty and social disruption as key determinants of the growing incidence of TB in Eastern Europe.[152]

Currently, most documented advocacy and communications efforts relating to Roma and TB marked with a double "X" focus on educating the Roma community about the biomedical determinants and course of TB, as well as service availability. DOW has conducted some other advocacy activities, but mostly on an ad hoc basis as they sought to eliminate difficulties to implementation of their planned project. In addition, DOW provided support to Roma peer health educators and mediators in designing advocacy projects. Some of these projects entailed Roma educators and mediators sharing information with local TB staff and encouraging collaboration.

Conclusions and Recommendations

There are few models for addressing the social determinants of TB transmission and control.[153] This gap poses particular challenges when looking at TB among excluded populations in middle income countries, because these countries have adequate technical expertise and infrastructure. In these cases, socioeconomic and political concerns might be the most important factors in determining the spread of TB. The following points attempt to fill some of this gap by providing both general conclusions and recommendations as well as suggestions for specific interventions.

General Conclusions and Recommendations

- Additional research is required on TB incidence and prevalence in the Roma community, as well as its determinants and the reasons for the community's failure to obtain diagnosis or adhere to treatment. Research should seek both quantitative and qualitative information, particularly relating to stigma, knowledge, cultural, geographic, and any other barriers. The possible influence of direct and indirect discrimination should be considered as well.

- The ethnic elements of Roma vulnerability to TB must be considered in both research and interventions. However, with the exception of broad efforts to end health system discrimination, most TB-specific programming should target geographic areas, and not ethnic groups. While poverty-related barriers to TB control disproportionately affect Roma, they limit access for all poor people. Moreover, ethnically-specific interventions would likely reinforce stereotypes about Roma and infectious disease, possibly increasing stigma and discrimination.

- Given existing information about the particular exclusion and access concerns of Roma women, the gender elements of TB vulnerability, stigma, diagnostic delay, and treatment adherence should be assessed and incorporated into programmatic planning. Investigators should go beyond collecting ethnic and gender disaggregated data, and should explore gender-specific issues, such as marriageability, health care and financial decision making, and childcare.

- Community level interventions should be paired with interventions to impact the functioning of the TB program. Improving TB knowledge and reducing TB stigma in the Roma community will have little impact if health care workers continue to perpetuate stigma or turn away Roma who respond to health education campaigns and seek medical care.

- Efforts to address TB must be linked with comprehensive efforts to improve overall access to health care. Economic concerns arise as major barriers in almost all assessments of Roma health. In some cases, the appropriate response might not be transport vouchers for TB treatment, but the construction (or re-opening) of health care facilities in under-served settings, or reforms to the health insurance system to better cover the poor. Indeed, many obstacles to TB diagnosis and treatment limit Roma access to health care in general. While stop gap measures to address an infectious disease may be appropriate, health care access limitations should be addressed on a systemic, rather than a disease-specific, basis.

- Similar to CDC recommendations on the prevention of control of TB in U.S. communities with at-risk minority populations,[154] Roma should be involved in program design and implementation. Low-cost community participatory interventions would use existing capacity and could have community-wide benefits. Involving Roma in research and program implementation would not only ensure effectiveness, but would also lessen social exclusion and contribute to community health literacy.

- Given that HIV rates are expected to continue to increase in Eastern Europe,[155] governmental and nongovernmental health programers and researchers should include HIV and Roma vulnerability to HIV in their planned research and/or interventions.

- Diagnostic delay or treatment interruption due to patient concerns about cost threatens overall TB control, as transmission to others becomes more likely.[156] Whether through national level efforts to publicize and enforce the policy that TB

diagnosis and treatment are free or local level interventions such as incentive programs, program designers should mitigate the impact of out-of-pocket payments on the poorest patients. Existing data about cost sensitivity among the Roma suggests that analysis and remedy of economic barriers is germane to addressing TB in Roma communities.

Recommendations and Conclusions Regarding Specific Interventions

- In-patient treatment
  - It is the responsibility of a health system to accommodate the social, economic, and cultural needs of its population. Indeed, several agencies and research reports have said that TB diagnostic or treatment failure is a failure of the system, not the patient.[157] Identifying and remedying such barriers is a key element of the DOTS strategy.[158] Since DOTS treatment in Eastern Europe usually entails two months of hospitalization, the health system should develop ways of accommodating practices relating to food and family presence. Alternatively, national TB control programs requiring two months of in-patient care should re-evaluate the necessity of this practice. Two months of in-patient care without expected family support and culturally-appropriate meal practices threatens the success of the intensive phase of TB treatment.

- Case finding
  - X-ray screening is likely not appropriate. It is costly, cannot easily be combined with other health projects, and often requires that patients travel to a health facility.
  - Door-to-door TB education and symptomatic case finding may be effective in the highest prevalence settings, but such a high-profile intervention should be approved by the community. Moreover, given the fact that discrimination and mistreatment of Roma patients has been repeatedly documented, a top-down public health approach such as active case finding must be approached with extreme caution. Implementers of such programs would ideally be Roma. Case finding would likely better address the priorities of Roma communities themselves (and avoid exacerbating stigma by conducting a visible search for Roma suspected of carrying an infectious disease) if it were paired with other efforts to increase access to health care.

- Patient support programs to ensure treatment completion
  - Comprehensive patient support to facilitate treatment adherence is part of both the International Standards of TB Care[159] and the Global Plan to Stop TB.[160]

National TB Programs and partner agencies should pursue scale-up of effective programs, including facility-based patient support, that have been implemented in the region. Moreover, they could explore the feasibility of implementing community-based interventions (such as TB patients' clubs) that have been implemented elsewhere in the world. Roma organizations that currently do community-based health work should be involved in the assessment, planning, and implementation of such interventions.

- Studies from the region show that substance abuse,[161] homelessness,[162] alcoholism, unemployment, and past incarceration[163] are key determinants of challenges to treatment adherence. Strategies for TB patient support should endeavor to address these specific challenges among patients of all ethnic backgrounds.

- Incentives
  - In many cases, incentives are much more than products to encourage treatment completion, but are necessary supplements to ensure the patient is not malnourished, to remove treatment barriers posed by absolute poverty, or to compensate for lost income. Many HIV/AIDS program implementers and treatment advocates have asserted that support for good food and nutrition and transportation should be an integral part of any treatment program.[164] The TB community is moving toward this consensus as well, as the new Global Plan to Fight TB 2006–2015 emphasizes the importance of addressing poverty in TB control,[165] and the World Food Program and WHO are developing guidelines for food assistance in the context of tuberculosis care and treatment. TB control programs with such a component would be consistent with emerging international best practices for TB control among the most poor. It would be inappropriate for an incentive program to target Roma specifically, in part because all of the poor share many of the same challenges to TB diagnosis and treatment completion. However, implementation of such a program in a region with high TB prevalence, low case detection, or low treatment adherence might remedy some limitations to TB diagnosis and treatment completion among Roma in the region, particularly given the role of economic barriers in limiting Roma access to TB services. Provider incentives and education may lessen some of the provider unwillingness to address the Roma.

- Advocacy and health communication
  - The absence of data and comprehensive efforts addressing TB in the Roma community is striking. Many strategies, poverty analyses, and Global Fund programs refer to heightened TB prevalence and vulnerability, but there are few activi-

ties aiming to collect more nuanced data or to address the problem through broad-based participatory programming. Most efforts are short-term efforts to detect incident cases. The paucity of data and programming highlights a need for advocacy to European and national level health policymakers. They need to be educated about existing data, the broader context of limited access to health care among the Roma, and the epidemiological costs of failing to consider social exclusion in TB control.

– Any bio-medical interventions to address TB among the Roma community should address political commitment gaps at all levels. Given the larger health policy context of decentralization in Eastern Europe, increasing commitment at the national level is insufficient. A multilevel approach would improve policy and commitment at the top, implementation capacity at the local level, and demand and capacity for participation at the bottom. Such an approach is also consistent with the Global Plan, which emphasizes political commitment, national and local level efforts to decrease barriers to TB care access for the poor, and community and patient participation.
– Given the DOW data about the impact of health education efforts and the seeming prevalence of TB stigma in Roma communities (at least in Romania), it is likely that health education could successfully improve knowledge and boost case detection in other settings. However, as mentioned, this "demand side" intervention should be accompanied by efforts to improve the quality of care. Moreover, the content of health education should also respond to the priorities articulated by Roma communities themselves. This might mean incorporating TB education into reproductive health, health insurance coverage, and other community health campaigns.

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Public Health Program

The Open Society Institute's Public Health Program promotes health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with local, national, and international civil society organizations to foster greater civil society engagement in public health policy and practice, to combat the social marginalization and stigma that lead to poor health, and to facilitate access to health information.

Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

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The World Bank, the United Nations Development Program, and the Council of Europe all report that TB is more prevalent in Roma communities and that the Roma are more vulnerable to TB. Yet Ministries of health in Eastern European countries with large Roma populations generally do not collect ethnically disaggregated data. As a result, health professionals, researchers, and advocates continue to face difficulties in discerning the barriers to TB control in Roma communities, the prevalence of TB among the Roma, and the factors that shape Roma vulnerability to TB.

The sparse data and few studies that do exist indicate a growing problem: in Slovakia, TB rates have declined more slowly for Roma than among the non-Roma population; in Romania, two Roma communities had a TB incidence significantly higher than the national average throughout the 1990s; and in Serbia, one Roma community had a TB prevalence rate more than 2.5 times higher than the national average.

Confronting a Hidden Disease: TB in Roma Communities outlines the available data on Roma and TB in Central and Eastern Europe and current efforts by governments and governmental agencies to address TB in Roma communities. The report aims to bring research needs and program opportunities to the attention of international agencies; national TB programs; ministries of health, social affairs, or minority integration; and NGOs.

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