

**Title:** The Modern Profile of Tuberculosis: Developing the TB Social Survey to understand contemporary social patterns in tuberculosis

**Running head:** Developing the TB Social Survey

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**Abstract**

Social disparities in tuberculosis have been documented for decades, yet to date there has not been a comprehensive study to examine the contemporary causes of these disparities. Local public health departments, and particularly public health nursing staff are charged with delivering directly observed therapy to individuals with tuberculosis disease. As a result of the frequency and duration of treatment, practitioners delivering therapy are often well-acquainted with the lives and challenges of their constituents. Thus, through these practitioners there exists a deep repository of knowledge on the drivers of social disparities in tuberculosis disease. Partnering with local public health departments, we developed a survey instrument aimed at understanding the social profile of individuals with tuberculosis disease in metropolitan Detroit, Michigan. We discuss the development and implementation of the survey instrument as well as

32 challenges in developing partnerships between academic researchers and local public health  
33 practitioners. This study can serve as a framework for both academic researchers and public  
34 health practitioners interested in addressing social disparities in infectious disease.

35

## 36 **Key words**

37

38 Social determinants of health, health status disparities, nursing, public health practice,  
39 tuberculosis

## 40 **Social Disparities in Tuberculosis**

41 After decades of decline, the incidence of tuberculosis (TB) in the U.S. has levelled off  
42 with no signs of decline in recent years (Salinas et al., 2016). What remains are persistent and  
43 entrenched disparities in TB incidence along lines of social disadvantage. There is a long history  
44 of social disparities in TB in the U.S. Despite the ubiquity of TB exposure during the 19<sup>th</sup> and  
45 early-20<sup>th</sup> centuries, TB disproportionately burdened socially disadvantaged populations,  
46 particularly racial/ethnic minorities, immigrants, and those in poverty. Social disparities in TB  
47 incidence continue to persist in the U.S. today. While the roots of these disparities are decades  
48 old, the contemporary causes are not well understood.

49 Currently, TB still disproportionately affects the foreign-born, racial/ethnic minorities,  
50 the poor, those living in urban environments, the homeless, and the incarcerated (Driver et al.,  
51 2007; Ellis et al., 2002; Alami et al., 2014). The incidence of recently transmitted TB in the  
52 United States is six times higher in Blacks compared to Whites (Noppert et al., 2017).  
53 Disparities are even larger in specific states, such as Michigan. From 2004-2012, the average  
54 incidence of recently transmitted TB in Michigan was nearly twenty times greater in Blacks than  
55 Whites (Noppert et al., 2017). Similarly, the average incidence of reactivation of latent TB  
56 infection (LTBI) in Michigan was 19 times greater in the foreign-born compared to the U.S.-born  
57 (Noppert et al., 2017).

58 Despite evidence of significant social disparities, reports on the trends and distribution of  
59 TB in the U.S. are based predominantly on surveillance data, which lack the detailed individual-  
60 level data to fully understand the reasons for these persistent disparities. While there is an

61 acknowledgement that TB disparities exist among certain subpopulations (i.e. among  
62 racial/ethnic minorities and socio-economically disadvantaged individuals), there is a lack of  
63 research on other social factors that could help to identify the underlying mechanisms by which  
64 these populations remain at greater risk. The purpose of this study was to develop a survey  
65 instrument aimed at systematically collecting detailed data on the social experience of  
66 individuals with TB.

### 67 **Lack of Data to Understand the Reasons for Social Disparities**

68 The paucity of research on the mechanisms underlying the social disparities in TB is  
69 driven, in part by, a lack of detailed data on the social and economic circumstances of current TB  
70 patients. In her 2000 paper, Acevedo-Garcia put forth a framework for understanding how one  
71 social process, residential segregation, may impact the epidemiology of TB (Acevedo-Garcia,  
72 2000). However, the extent to which we can operationalize this framework across contexts, or  
73 extend it to include other social processes is hampered by the lack of data of this nature.  
74 Moreover, there are increasing calls for those in infectious disease research to employ the tools  
75 of social epidemiology to better address social disparities in infectious diseases (Cohen, Wilson,  
76 & Aiello, 2007; Noppert, Kubale, & Wilson, 2016). Our ability to do so, however, is dependent  
77 on the collection of contemporary data on the social profile of TB patients.

78 Much of what we know about the social experience of individuals with TB in the U.S. is  
79 derived from evidence (both formal and anecdotal) that is decades old. Current socio-  
80 demographic data is limited to what is available on the patient chart and the “Report of a  
81 Verified Case of TB” (RVCT) form produced by the Centers for Disease Control and Prevention  
82 (CDC) (Centers for Disease Control and Prevention, n.d.). These data are often based on  
83 clinician observation and are mainly focused on collecting data on known TB risk factors. To  
84 date, very few studies have been able to ascertain detailed socio-demographic data on TB  
85 patients. However, these types of data exist informally at the local public health level,  
86 particularly among those charged with carrying out directly observed therapy (DOT).

87 DOT is a central tenet to the care of individuals with TB in the U.S. (Centers for Disease  
88 Control and Prevention, 2013) To carry out DOT, a health practitioner, most often a public  
89 health nurse, must observe the individual with TB taking the prescribed medication on a regular  
90 basis. Given the long duration of TB drug therapy (typically 4-6 months) and the regularity with

91 which medications must be taken, the practitioner often inadvertently becomes involved in the  
92 patient's life.

93 Thus, while academic researchers may lack the requisite data to bridge the gaps between  
94 observed disparities and the drivers of those disparities, public health practitioners are keenly  
95 aware of the complex interplay between TB disease and the social and economic status of  
96 individuals. Yet, this knowledge has not been collected in a systematic way that would allow for  
97 wider use by both the research community and by those designing policies and interventions for  
98 TB control.

### 99 **Developing a Survey Instrument to Understand Social Disparities**

100 To address the lack of data on social and economic factors that could be underlying  
101 persistent TB disparities, we developed a survey instrument aimed at systematically collecting  
102 detailed data on the social experience of individuals with TB. We pilot tested the instrument in  
103 metropolitan Detroit, Michigan, an area with ongoing incidence of TB. Our study had two  
104 primary aims: one, to develop a survey instrument that could be utilized by local public health  
105 agencies; and two, to gather detailed data on the social and economic profile of TB patients in  
106 metropolitan Detroit. Our purpose in this paper is to discuss the process of developing the survey  
107 instrument; the study infrastructure for implementation of the instrument; and challenges in  
108 developing partnerships between academic researchers and local public health practitioners.  
109 Although the survey is ongoing and data continue to be collected, our goal is that this survey  
110 instrument can ultimately be implemented at the national level to yield important insights into  
111 the modern TB epidemic in the U.S., and facilitate the effective allocation of resources to those  
112 most at risk.

## 113 **Methods**

### 114 **Target Population and Study Site Recruitment**

115 Our target population was individuals with TB in metropolitan Detroit. From 2007-2012,  
116 the incidence of TB disease in Detroit was 58% greater compared to outside of Detroit. The three  
117 health departments recruited for participation in this study accounted for 55% of all TB cases in  
118 Michigan from 2007-2012 (data taken from MDHHS surveillance data).

119 In order to recruit study participants from this population, we partnered with three local  
120 public health agencies carrying out DOT in this area: Oakland County Division of Health,

121 Wayne County Health Department, and the Physicians Group at Wayne State University. The  
122 three study sites were chosen in collaboration with the TB control staff at the Michigan  
123 Department of Health and Human Services (MDHHS). MDHHS staff identified local public  
124 health agencies who served the largest patient populations in metropolitan Detroit. Once  
125 identified, the research team at the [ANONYMOUS FOR REVIEWING] contacted the local  
126 public health agencies and invited each site to participate in the study.

127 Our collaborations were formalized after months of rapport building between the research  
128 team at the [ANONYMOUS FOR REVIEWING] and practitioners at the local level. Our formal  
129 collaboration with each health department also included joint IRB approvals between the  
130 MDHHS, the [ANONYMOUS FOR REVIEWING] and each individual health department. The  
131 study team at the [ANONYMOUS FOR REVIEWING] provided a one day training in survey  
132 administration and human subjects' protection at each study site.

### 133 **Study Design**

134 This project is a pilot study, the purpose of which was to develop a survey instrument to  
135 be used in community public health settings to ascertain the social status of individuals with  
136 active TB disease. In the U.S., TB is a notifiable disease whose treatment is covered by the state  
137 health resources. As such, each case of TB disease is reported to the local health department  
138 (usually county-level) who then facilitates treatment. We decided the survey instrument could  
139 most efficiently be delivered by utilizing the existing infrastructure of local public health  
140 agencies, which have both a record of all existing cases in their catchment area as well as regular  
141 contact with such individuals. The survey is administered by the healthcare workers overseeing  
142 DOT to persons with TB.

143 The survey is given at one time point during the drug therapy period. When planning for  
144 survey administration, it was decided in collaboration with the health departments, that surveys  
145 should be administered once rapport has been built between the individual with TB disease and  
146 the health care professional, a minimum of four weeks into therapy.

### 147 **Survey Participant Recruitment**

148 Inclusion criteria for participation in the study included: individuals with active TB  
149 disease identified at one of the three participating metropolitan Detroit health departments; any  
150 individual currently in treatment or who had completed treatment in the last year; ability to speak

151 and understand English; and over the age of 18. Healthcare professionals administering DOT  
152 invited each individual to participate in the study. The healthcare professional explained the  
153 purpose of the study as well as any risks associated with participation in the study. Written  
154 informed consent was obtained from each individual participating in the study. Survey  
155 participants were offered a one-time \$20 incentive for participation in the study in the form of a  
156 gift card to a local grocery store.

## 157 **Survey Development**

158 The process of developing a survey instrument to fit the needs of this specific patient  
159 population was an iterative process spanning months, and involving many different parties. The  
160 survey needed to accomplish three main objectives: one) collect detailed socio-demographic  
161 variables relevant to the lives of persons with TB disease in a standardized format; two) collect  
162 these data in a manner feasible for the participants, study team, and the health department staff to  
163 carry-out; and three) create buy-in from both the state and local health departments to carry out  
164 the study.

165 In designing the survey instrument, we collated months of information that had been  
166 gathered from meetings with state and local TB control staff. Given the regularity of contact and  
167 length of treatment for TB disease, local public health agencies often have a deep repository of  
168 invaluable anecdotal data on the social and economic lives of their constituents. To leverage this  
169 knowledge, we spent months talking with local TB control staff by sitting in on cohort reviews  
170 of the current TB patients receiving treatment and through one-on-one conversations with the  
171 staff. We then used this knowledge to begin constructing the survey instrument.

172 We also examined the RVCT form to identify either components missing from the form  
173 or questions that were based on clinician observation rather than patient self-report. We used this  
174 information to identify the key question themes that should be addressed by the survey.

175 Where possible we used questionnaire items from national surveys and major cohort  
176 studies that were valid and reliable to begin compiling potential questions. These studies  
177 included: the Jackson Heart Study (Taylor et al., 1999), the Detroit Neighbor Health Study  
178 (Goldmann et al., 2011), the Multi-Ethnic Study of Atherosclerosis (Bild et al., 2002), the U.S.  
179 Health and Retirement Study (Juster & Suzman, 1995), and the Americans' Changing Lives  
180 Study (Lantz, House, Mero, & Williams, 2005). However, for those themes for which we could  
181 not find an adequate question, we developed our own.



182 The purpose of the survey instrument was to understand the current social profile of TB  
183 patients in terms of their basic demographics, social status, and economic status. We also wanted  
184 to gather evidence on what their social profile was before they were diagnosed with TB. We did  
185 this explicitly with questions asking them to recall their status before diagnosis. However, in  
186 some cases we also assumed that current life circumstances could be used as a proxy measure for  
187 their conditions before TB diagnosis. We hypothesized that social factors may have a role in  
188 patterning not only one's risk of progressing to active TB disease, but also the probability that  
189 one is exposed to Mycobacterium tuberculosis (MTB), the pathogen causing TB disease.

190 The final survey, entitled the "TB Social Survey" was split into three main parts:  
191 demographics, life before TB, and current status (Table 1). In the demographics section of the  
192 survey participants were asked about their race/ethnicity status, gender, marital status, and  
193 educational status. The next section was composed of questions designed to ascertain details of  
194 the participants' life before TB. Included in these were questions about general health status,  
195 health behaviors, including health-seeking behaviors, and locations frequented in the community.  
196 Asking about locations frequented in the community was an attempt to understand the places  
197 where an individual may have been exposed to the MTB pathogen. Finally, the largest section of  
198 the survey was devoted to understanding features of the individuals' current life. These  
199 questions encompassed housing conditions (e.g. history of homelessness, transient housing, and  
200 living conditions); neighborhood conditions; current health insurance; employment and income  
201 status (including ability to pay bills); subjective social status; and food security. The final survey  
202 includes 30-questions, and takes approximately 20-25 minutes to administer. We pre-tested the  
203 survey for three months before survey launch. Pre-testing was done among ten individuals  
204 without TB, including eight women and two men, with a range of incomes. Nine of the ten  
205 individuals were 30-40 years of age. Further, before survey launch each health department gave  
206 feedback on the survey which was incorporated into the final survey. The final survey instrument  
207 was provided to each health department before the formal launch of the study. IRB approval was  
208 obtained for the collection of the survey data at each study site and at MDHHS. For the complete  
209 survey instrument see Supplemental Digital Content 1.

210

## 211 **Preliminary Findings**

### 212 **Characteristics of the Study Population**

213 To date, a total of 26 individuals were recruited to participate in the study; 23 completed  
214 the survey for a survey completion rate of 88.46%. Of the 23 participants, 65% were from the  
215 Wayne County Health Department; 22% from the Oakland County Division of Health, and 13%  
216 from the Physicians Group at Wayne State University (Detroit City Health Department).

217 Characteristics of these participants are presented in Table 2. Of the 23 individuals with  
218 completed surveys, 39% were U.S-born, 48% foreign-born and 13% were missing data on  
219 nativity (Table 2). The participants were 30% Black/African American, 26% White, 22% Asian  
220 Indian, and 22% some other race. Additionally, 26% of the sample identified as Middle Eastern /  
221 North African descent. Over half (65%) of the participants were female and the mean age was  
222 42.4 years. The study is ongoing but will likely continue to replicate the sociodemographic  
223 patterns observed to date.

224 Responses to a subset of survey questions are given in Table 3. We asked participants a  
225 series of questions about their health before their diagnosis of TB. Regarding their health before  
226 diagnosis, 91% of participants reported that they were in good or excellent health and 30%  
227 reported having smoked cigarettes before their diagnosis. Finally, before TB the majority (70%)  
228 of participants reported engaging in active sports or exercise at least once per week.

229 We also asked participants about their current life including income, living conditions,  
230 and their neighborhood environment. While 35% of the sample refused to report their income,  
231 17% reported an income less than \$15,000; 13% reported an income between \$15,000 and  
232 \$30,000; 13% reported an income between \$30,000 and \$75,000; and 4% reported an income  
233 greater than \$75,000. 39% of the sample reported some difficulty making monthly bill payments.  
234 Over a quarter (26%) of participants reported some difficulty making food last until there was  
235 money to buy more.

236 When asked about their current living conditions, 96% of participants reported having a  
237 permanent address; 4% reporting living in a public housing project. Moreover, 87% of the  
238 sample rated the condition of where they lived as good or excellent.

239 Item nonresponse was notable in our study for the income question. The section of the  
240 survey regarding income was placed at the end of the survey. Thirty-five percent of participants

241 refused to answer this question at all. Seventeen percent of participants reporting not knowing  
242 their totally household yearly income.

243 The data presented here are preliminary results. Data collection will continue through  
244 2017. We expect to have approximately 70 participants total from all three health departments.

245

## 246 **Insights and Future Implications**

247 As far as we are aware this is the first standardized survey instrument developed to  
248 collect data on the social profile of TB. The process of carrying out the study as well as the  
249 preliminary results offer important insights into the socio-demographic profile of TB patients in  
250 metropolitan Detroit. Ultimately, we hope the process of ascertaining detailed socio-  
251 demographic information on TB patients will be replicated in other health departments both in  
252 Michigan, and nationally. In addition, we hope our findings will be used to guide TB control  
253 efforts, particularly in metropolitan Detroit where limited resources need to be allocated  
254 efficiently and effectively.

255 Our preliminary results allow us to begin to understand the modern socio-demographic  
256 profile of individuals with TB in the U.S. For instance, asking about individuals' living  
257 conditions, ability to make bill payments, and food availability gives us critical information on  
258 the social vulnerability of an individual. A large portion of participants (39%) have thus far  
259 reported some difficulty making monthly bill payments and 26% reported some difficulty  
260 making food last. These data suggest that there may be underlying insecurity with accessing  
261 basic resources. This insecurity may have implications for overall health status likely increasing  
262 probability of developing active TB disease once exposed to MTB.

263 These findings may also give us important insights into how we might best design  
264 interventions that improve the health conditions of individuals with TB. For example, it is likely  
265 that many of those receiving treatment for TB disease may also benefit from assistance in getting  
266 access to food. While many health departments delivering TB care work to address these needs,  
267 our findings can provide evidentiary support for increased funding for such interventions.

268 We encountered several key methodological challenges in this study: namely, non-  
269 participation in the survey and item non-response for particular questions. We examined reasons  
270 for both occurrences in order to design strategies to mitigate the resulting bias in the future as  
271 well as to understand how the survey should be modified in future iterations.

272 Nationally, survey non-participation is increasing (Massey & Tourangeau, 2013). This  
273 increase is most notable in cross-sectional surveys in which researchers do not have the benefit  
274 of offering consistent financial incentives over time (Massey & Tourangeau, 2013). Further, non-  
275 participation is more likely to occur among the disadvantaged: minorities, males, urban residents,  
276 single persons, the poor, and those with fewer social ties and attachments (Schoeni, Stafford,  
277 McGonagle, & Andreski, 2013)—precisely the population we were most interested in studying.

278 Massey and Tourangeau give three primary reasons for non-participation: noncontact—  
279 interviewers being unable to make contact with potential participants; refusals—contact is made  
280 but participants decline to participate; and a residual category encompassing such reasons as too  
281 busy, sick, participant/interviewer differences (Massey & Tourangeau, 2013). Refusals  
282 consistently account for the largest proportion of unit nonresponse—typically 60-65% (Brick &  
283 Williams, 2012). In our study, noncontact was less of an issue given that potential participants  
284 were individuals enrolled in TB treatment. Refusals were, however, the primary reason for  
285 nonresponse. Since the interviewer has an established rapport with participants prior to the  
286 administration of the survey, we were able to gather anecdotal evidence for the reasons for  
287 nonresponse. Most of our refusals noted were among foreign-born persons who expressed fear  
288 of their data being transmitted to the U.S. government. The healthcare workers noted that the rate  
289 of non-participation from foreign-born persons seemed to increase in times when contemporary  
290 immigration fears and policies were amplified in the public. They also noted this seemed more  
291 of an issue with newly arrived immigrants as opposed to those with established residency in the  
292 U.S. Thus, despite the one-time financial incentive we offered survey participants, the risks and  
293 threats to confidentiality outweighed the financial incentive for this particular population.

294 Item nonresponse, or refusing to answer specific questions, was also a methodological  
295 challenge we faced. Nationally, rates of item nonresponse are also increasing, particularly for  
296 sensitive questions such as those dealing with income and receipt of government benefits  
297 (Meyer, Mok, & Sullivan, 2015). Meyer, Mok, and Sullivan hypothesize three reasons for item  
298 nonresponse: refusal to answer, inability to answer, or failure of the interviewer to accurately  
299 record the participant response (2015). Item nonresponse was notable in our study in terms of the  
300 income question. Over 35% of participants refused to answer this question at all. All three of the  
301 above factors certainly influenced participants' willingness to answer the income question in our  
302 study. Some participants simply refused to answer the question while others cited a fear of

303 disclosure of private information to the U.S. government. Others were simply unable to answer  
304 the question either because of language difficulties or being a member of a family unit in which  
305 he or she is not privy to such information.

306 The third explanation for item nonresponse, that of the failure of the interviewer to  
307 accurately record a response, applies both to the income-related questions in our survey as well  
308 as to a number of other sensitive questions. In some instances, the response given to a certain  
309 question was too obscure and time-consuming for the healthcare worker to disentangle and  
310 indicate on the survey. In these cases, the healthcare workers reported they would skip recording  
311 a response to the question. We also saw a related issue in our survey—failure of the interviewer  
312 to ask the question. In our survey training, we gave interviewers the autonomy to decide whether  
313 or not to ask a question based on verbal and nonverbal cues from the participant. The healthcare  
314 workers indicated that questions of a sensitive nature such as income, housing, and social  
315 standing sometimes visibly upset the participant. On such occasions, the healthcare worker  
316 would simply not continue with the question or its related questions. One step we would like to  
317 implement in future iterations of the survey is the addition of an item on each question indicating  
318 if the interviewer skipped asking the question altogether. This may help us disentangle refusal to  
319 answer a question, inability to record a response, and failure to ask a question from one another.

## 320 **Lessons Learned and Next Steps**

321 In addition to the strengths and limitations of the study itself, there were several lessons  
322 we learned with regards to developing collaborations between academia and local public health  
323 agencies. One of the most critical lessons was the need for buy-in from all stakeholders. The  
324 local public health agencies were keenly aware of the needs and challenges of their patient  
325 population and thus were able to give critical feedback on the survey instrument itself as well as  
326 the logistics of carrying out the study. Throughout the duration of the study, we found it helpful  
327 to continually cultivate the relationships with the local public health agencies, particularly the  
328 public health nursing staff. Often these practitioners are working within resource constrained  
329 environments and may have many demands on their time. The study team held a lunch meeting  
330 twice per year for each local public health agency in order to provide a time and space for the  
331 staff to give feedback on the progress of the study, to problem solve any issues, and to continue  
332 to build rapport between the two stakeholders.

333            Launching the study initially required much more time than we anticipated due to having  
334 to obtain multiple IRB approvals across study sites. In the future, we would allocate much more  
335 time for this process and set up structures to deal with any potential issues that may arise during  
336 each IRB approval process.

337            There are several major strengths to this study that can offer direction to future studies.  
338 First, to our knowledge there has not been a study such as this conducted in the modern U.S.  
339 context. This is one of the first studies to utilize a survey instrument to collect detailed socio-  
340 demographic information on individuals with TB. It is our hope that the data we obtain from our  
341 survey can provide insights into why the TB epidemic has continued in the U.S., and moreover  
342 why disparities in TB incidence continue to persist.

343            Another key strength of our study is that it allows participants to self-report their socio-  
344 demographic characteristics as opposed to the previous reliance on health care worker  
345 observation on the RVCT form. How an individual identifies oneself can be much more  
346 indicative of their social experience than how a healthcare worker may identify them.

347            Our study has also developed a framework for collaborations between state/local health  
348 departments and academia around issues of TB control. Such collaborations are mutually  
349 beneficial and can result in data that can better inform both TB control and TB research. For  
350 example, the health departments that participated in this study are utilizing the data from this  
351 study as well as input from the researchers to develop grant applications for increased funding  
352 for their TB control programs. The health departments also noted the benefit of having more  
353 detailed data to report out to the state and city health officials; such data highlights the need for  
354 sustained funding for infectious disease control programs, such as TB control. Finally, the health  
355 departments have articulated a desire to apply this methodology to other infectious diseases  
356 under the jurisdiction of the local health department.

357            There are also several limitations to our study. While there are many benefits to the  
358 survey being administered by healthcare workers (i.e. rapport, trust), some participants were still  
359 fearful of the consequences of their participation for the quality of their care. The healthcare  
360 workers consistently reported that nativity was an important factor influencing how questions  
361 were interpreted. For example, foreign born participants questioned whether they should report  
362 their highest education based on U.S. metrics or based on the years of education in their country  
363 of origin. Given the high proportion of foreign-born persons in the TB population, it would be

364 beneficial to tailor certain questions to better fit the needs of the foreign-born population.

365 Further, the results of this study are prone to recall bias, particularly for the series  
366 of questions in which participants were asked to recall the time before they had TB. For some  
367 participants, this may have been up to one year ago. Moreover, because of recall bias, we suspect  
368 that participants may have remembered their time before TB as better than it was in comparison  
369 to their current status.

370 Finally, since this is a pilot study, we do not have a control group without TB. We cannot  
371 compare our study results with a TB-free population which would allow us to quantify the  
372 degree to which certain variables put individuals at risk for TB. However, we believe having the  
373 baseline socio-demographic characteristics of this population will make such studies possible in  
374 the future.

375 In spite of these limitations, this study provides an instrument to systematically collect  
376 data on the social experience of TB patients. These data are critical to informing interventions to  
377 better address the TB epidemic in the U.S.

378 In future iterations of the study we would like to develop strategies to better ascertain  
379 information from individuals who feel at-risk—such as foreign-born persons. One way to do this  
380 might be to change the timing of survey administration. Many of the healthcare workers noted  
381 on-going healthcare related encounters with patients after treatment completion. Post-treatment  
382 healthcare encounters may present a more comfortable time for at-risk persons to be  
383 administered the survey both because they have increased rapport with the health care worker  
384 and they are no longer required to undergo treatment. Another way to ensure participation of at-  
385 risk individuals may be to have a patient advocate present for survey administration; someone  
386 such as a trusted family member and/or social worker. However, this may also diminish the  
387 individuals' likelihood of responding to certain questions.

388 Moreover, for public health agencies seeking to implement this tool, linking the data  
389 collected on the survey to treatment outcomes may be beneficial. For example, understanding if  
390 treatment adherence is tied to any particular social vulnerability may be insightful for the health  
391 department staff. Treatment completion is of critical importance to both the health of the  
392 individual and reducing the development of drug resistant forms of the MTB pathogen.

### 393 **Implications for Public Health Practice**

394 The findings of this study can aid public health practitioners at both the local and national

395 levels. At the local public health level, these data could provide those in TB control a better  
396 understanding of which populations continue to be at-risk for TB such that control strategies  
397 could be tailored accordingly. Implementing this survey at public health departments nationwide  
398 could provide critical data on the current landscape of TB in the U.S. Such data could provide  
399 insight in how to best allocate limited resources and design interventions that would move the  
400 U.S. closer to TB elimination.

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## **Supplemental Digital Content**

The survey instrument is included as a supplemental digital content:

supplementaldigitalcontent1.pdf

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## Tables

**Table 1.** Major components of the TB Social Survey.

Survey Section	Specific Variables
<b>Part 1:</b> Demographics	Race Gender Marital Status Education
<b>Part 2:</b> Life Before TB	Self-rated health Alcohol usage, past and current smoking behavior, physical activity Healthcare-seeking behaviors, barriers to seeking healthcare Locations frequented throughout the community
<b>Part 3:</b> Current Status	Housing (history of homelessness, transience in housing, crowded housing condition) Neighborhood condition Health insurance, barriers to having health insurance Employment Income (including ability to make monthly bill payments) Subjective social status Access to social support Food security

**Table 2.** Preliminary results of the TB Social Survey. The following table describes the demographic characteristics of the preliminary study sample (N = 23).

<b>Variable</b>	<b>Mean</b>	<b>Std. Dev.</b>
Age (Mean) Missing = 3	42.4	17.38
	<b>N</b>	<b>%</b>
<b>Nativity</b>		
U.S.-born	9	39.13
Foreign-born	11	47.83
Missing	3	13.04
<b>Race/Ethnicity</b>		
Black/African American	7	30.43
White	6	26.09
Asian Indian	5	21.74
Other	5	21.74
<b>Middle Eastern/North African descent</b>	6	26.09
<b>Hispanic descent</b>	2	8.70
<b>Gender</b>		
Male	8	34.78

Female	15	65.22
<b>Marital Status</b>		
Married	10	43.48
Separated	1	4.35
Divorced	2	8.70
Widowed	3	13.04
Living with a partner	2	8.70
Single	5	21.74
<b>Education</b>		
Some high school	3	13.04
High School/ GED	7	30.43
Some college	5	21.74
Bachelor/Associate	5	21.74
Other Professional degree	2	8.70
Missing	1	4.34

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\*Results based on preliminary analyses of 23 individuals

**Table 3.** Preliminary results of the TB Social Survey. The following table describes the participant responses to select questions from the TB Social Survey (N = 23).

Variable	N	%
<b>“Before you had TB, would you say your health was excellent, good, fair, or poor compared with other people your age?”</b>		

Excellent	10	43.48
Good	11	47.83
Fair	2	8.70
<b>“Did you ever drink beer, wine, or liquor?”</b>		
Yes	8	34.78
No	15	65.22
<b>“Did you smoke cigarettes before you had TB?”</b>		
Yes	7	30.43
No	15	65.22
Missing	1	4.35
<b>“Have you ever smoked?”</b>		
Yes	6	26.09
No	13	56.52
Missing	4	17.39
<b>“Before your diagnosis of TB, how often did you engage in active sports or exercise?”</b>		
Never	5	21.74
< 1 x per week	2	8.70
Once a week	6	26.09
Multiple times per week	4	17.39
Almost every day	6	26.09
<b>“Do you have a permanent address?”</b>		
Yes	22	95.65
No	0	
Missing	1	4.35
<b>“Do you live in a public housing project?”</b>		
Yes	1	4.35
No	22	95.65
<b>“How would you rate the condition of where you live?”</b>		
Excellent	13	56.52
Good	7	30.43
Fair	2	8.70
Poor	1	4.35
<b>“How would you rate the quality of your neighborhood, that is the area within 2-3 blocks of where you live?”</b>		
Excellent	9	39.13
Good	10	43.48
Fair	2	8.70

Poor	2	8.70
<b>“How difficult is it for you to make your monthly bill payments?”</b>		
Not difficult	12	52.17
Somewhat	7	30.43
Very	1	4.35
Extremely	1	4.35
Refused	0	
Missing	2	8.70

**Table 3.** Cont.

Variable	N	%
<b>Total Household Yearly Income (\$)</b>		
< 15,000	4	17.39
15,000 - 30,000	3	13.04
30,000 – 75,000	3	13.04
> 75,000	1	4.35
Don't know	4	17.39
Refused	8	34.78
<b>“How difficult is it for you to make food last until you have money to buy more?”</b>		
Not difficult	17	73.91
Somewhat difficult	6	26.09
<b>“Have you had to cut down the number or size of meals because of money?”</b>		
Yes	2	8.70
No	21	91.30

\*Results based on preliminary analyses of 23 individuals