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Measuring Stigma to Assess the Social Justice Implications of Health-Related Policy Decisions: Application to Novel Treatment Regimens for Multidrug-Resistant Tuberculosis

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In making policy decisions with constrained resources, an important consideration is the impact of alternative policy options on social justice. Social justice considers interactions between individuals and society and can be conceptualized across domains of agency, association, and respect. Despite its importance, social justice is rarely considered formally in health policy decision making, partially reflecting challenges in its measurement. We define three criteria for considering social justice in health-related policy decisions: 1) linkage of social justice to a measurable construct; 2) ability to reproducibly and feasibly estimate the impacts of a policy decision on the selected construct; and 3) appropriate presentation to decision makers of the expected social justice implications using that construct. We use preliminary data from qualitative interviews from three groups of respondents in South Africa and Uganda to demonstrate that stigma meets the first of these criteria. We then use the example of policy addressing novel treatment regimens for multidrug-resistant tuberculosis and a validated tuberculosis stigma scale to illustrate how policy effects on stigma could be estimated (criterion 2) and presented to decision makers in the form of justice-enhanced cost-effectiveness analysis (criterion 3). Finally, we provide a point-by-point guide for conducting similar assessments to facilitate consideration of social justice in health-related policy decisions. Our case study and guide for how to make social justice impacts more apparent to decision makers also illustrates the importance of local data and local capacity. Performing social justice assessments alongside more traditional evaluations of cost-effectiveness, budget impact, and burden of disease could help represent data-informed considerations of social justice in health care decision making more broadly.

Keywords
drug resistance, health policy, social justice, social stigma, tuberculosis

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Introduction: Social Justice and the Economic Evaluation of Health Interventions

Decision makers in resource-limited settings must frequently choose which public health interventions to prioritize using severely constrained resources.[1] Economic evaluation (e.g., cost-effectiveness analysis) is widely used to aid in these decisions.[2] In its classic form, economic evaluation estimates the economic cost per health outcome (e.g., cost per death averted); both costs and

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effectiveness are typically measured at the level of the individual, and cost-effectiveness is estimated by summing those individual measures to construct a population-level estimate. This approach has known weaknesses when decision makers value outcomes (e.g., equity) that accrue to society rather than to individual people. Contemporary approaches to economic evaluation—for example, multi-criteria decision analysis[3]—seek to incorporate both individual-level and societal-level outcomes, but even these approaches break down when the outcomes of greatest importance to decision makers are difficult to quantify and involve interactions between individual people and society at large. One such outcome is *social justice*, understood as fairness in the distribution of policy impacts on multiple dimensions of personal well-being.[4,5] Public health decision makers who are concerned about disadvantaged populations might wish to consider social justice in their deliberations, yet formal methods for doing so are few and not widely applied.[6,7]

We seek to describe an applied example in which social justice could be formally considered in economic evaluations of health policy decisions, namely, novel treatments for multidrug-resistant tuberculosis (MDR-TB). In 2018, the World Health Organization issued new treatment guidelines for MDR-TB that eliminated daily injectable agents from the standard regimen and shortened the treatment course (for an important subset of patients) from 18–20 months to 9–12 months.[8] Novel regimens currently in late-stage clinical trials could further shorten this treatment course to 4 to 6 months.[9] Unfortunately, these newer treatment-shortening regimens are currently very costly.[10] While traditional economic evaluation has suggested that these regimens are likely to be cost-effective (at least under generous willingness-to-pay thresholds), the projected budget impact of a policy decision to switch to shorter-course, all-oral regimens for MDR-TB is sizeable.[11] Thus, cost-effectiveness analysis alone may be insufficient to justify adoption of such a policy. Explicit consideration of the potential social justice impacts of using novel, shorter-course MDR-TB regimens is well suited for this example because it could influence decision making.

For analytical methods to consider social justice in a way that public health decision makers can use, we argue that at least three criteria must be met. First, because social justice (which involves the *interaction* between individuals and society) cannot be directly measured at the individual or societal level, social justice must be reasonably linked to one or more constructs that are measurable. Here, we explore the use of *stigma* as a measurable construct that may characterize some of the social justice implications of a policy decision to adopt novel MDR-TB regimens. Second, a reproducible and feasible method must exist to quantitatively estimate (or at least categorize into discrete levels) the impacts of a policy decision on the selected theoretical construct. Many validated scales exist for stigma, and stigma has been widely studied in the context of TB treatment. Widely used scales, therefore, could be used to estimate the impact of alternative MDR-TB treatment policies on stigma—and by extension on social justice.[12] Third, these impacts must be presentable to decision makers in a fashion that faithfully and transparently represents the expected social justice implications of alternative policy decisions along with other relevant considerations (e.g., traditional cost-effectiveness). Earlier work illustrates how estimated stigma impacts might be presented alongside traditional considerations of cost-effectiveness to aid public health policy makers who would like to consider both social justice and cost-effectiveness in their decision making.[13] In the following sections, we explore each of these criteria in greater detail using an applied example.

Stigma as a Meaningful Representation of Social Justice

Our conception of social justice derives from a framework developed by Bailey and colleagues.[14] This framework centers on three core dimensions of human well-being that are important to consider in addition to health: *agency* (being able to lead one's life as one sees fit); *respect* (being recognized by others and oneself as having equal personal dignity and worth); and *association* (being able to engage in a full range of interpersonal relationships). A central element of this social justice framework is an understanding that certain policies may cause disadvantages to cluster across these three domains, thereby generating an overall experience (for

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individuals and society) that might be worse than would be expected by simply estimating impacts in each individual dimension. Avoidance of such "clustering of disadvantages" is prioritized in the social justice framework.[15,16] This social justice framework is thus inherently concerned with interactions between individuals and society and the potential for disadvantages to cluster across different domains. To be useful under this framework, any construct used to measure the social justice implications of specific policy decisions must also capture individual-societal interactions and cross-domain clustering.

Goffman defines stigma as an "attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one."[17] Stigma is often considered as consisting of four components: anticipated, perceived, enacted or experienced, and internalized stigma.[18] Anticipated stigma occurs when individuals change their normal activities and behaviors in fear of judgment and exclusion from their communities. Anticipated stigma could therefore have negative implications for *agency* and *association*. Perceived stigma typically refers to the awareness of stigma toward individuals (e.g., people living with MDR-TB) in a community and thus directly affects both *association* and *respect*. Enacted or experienced stigma refers to discrimination and prejudice exhibited toward individuals and may result in social isolation, loss of employment, and exclusion from family or relationships—negative outcomes in the domains of *association, respect*, and *agency*. Internalized stigma, also called self-stigma, refers to a person's feelings of contamination, shame, and self-rejection or self-loathing, and can therefore negatively affect *respect* and secondarily *agency*. Like the framework of social justice described above, stigma is intrinsically concerned with interactions between individuals and society. By evaluating the effects of health policy decisions across multiple components of stigma, it should also be possible to identify impacts across the domains of social justice as well.

Preliminary findings from in-depth interviews conducted by our team among 1) people being treated for MDR-TB in South Africa and Uganda, 2) health care providers who care for such people, and 3) members of communities affected by MDR-TB support a strong linkage between stigma and social justice (unpublished data). Specifically, when prompted to discuss elements of MDR-TB treatment that might affect the ability to lead one's life as one sees fit (*agency*), to be recognized as having dignity and worth (*respect*), and to engage in interpersonal relationships (*association*), all three groups of respondents, in both countries, mentioned experiences that encompass stigma as a dominant theme. Here, we build upon these preliminary findings to show how validated TB stigma scales could be applied to evaluate the social justice impacts of MDR-TB treatment policy decisions. We then briefly illustrate how this approach could extend to other health policy contexts and be used with alternative constructs beyond stigma.

Measuring the Effects of MDR-TB Policy on Stigma and Social Justice

Several stigma scales have been developed and validated for content validity, construct validity, and reliability in populations with TB;[19] one of the most commonly used scales was developed by Van Rie and colleagues in 2008.[21] No one stigma scale captures all four components of stigma described above, and most scales focus on only one.[18,19] For example, enacted stigma or discrimination scales help capture the social exclusion or discrimination experienced directly by patients, whereas the Van Rie scale focuses on the general community's perspectives on TB and therefore may best assess perceived (and perhaps anticipated) stigma. Very few scales attempt to measure self-stigma (i.e., internalized stigma) directly.

The Van Rie TB stigma scale is designed to measure social and psychological elements of TB stigma at both the community level and the individual level. This scale covers items across several domains including fear surrounding transmission and disease; willingness to interact with persons affected by TB; values and attitudes relating to shame, blame, and judgement; and disclosure of disease status.[21] The Van Rie scale was first developed for use in southern Thailand and was intended to provide a quantitative measure of both TB stigma and HIV/AIDS stigma through separate stigma scales for each disease. Scales were developed through in-depth interviews and focus groups with people living with TB, family members, health care workers, and community members to ensure content validity and that scale content was culturally and linguistically appropriate. The Van Rie TB stigma scale differentiates itself from other scales in its use of third person narrative, for example, "Some people may not want to eat or drink with friends who have TB." Respondents are asked to respond using a 4-point Likert-type scale where 0 represents the least amount of stigma (strongly disagree) and 3 represents the highest degree of stigma (strongly agree). A summary score is then calculated based on the sum of each item's response.

The Van Rie TB stigma scale consists of two sections. The first section includes 11 questions and focuses on assessing community perspectives on TB including items,

such as, "If a person has TB, some community members will behave differently toward that person for the rest of his/her life." Many of these elements can be directly mapped onto impacts on *association* and *respect*. The second section includes 12 items focusing on patients' perspectives toward TB and include items, such as, "Some people who have TB feel hurt of how others react to knowing they have TB" or "Some people who have TB lose friends when they share with them they have TB." Many of these elements can be mapped onto one or more of *association, respect*, and *agency*. The scale has now been translated and validated for use in several different populations ranging from Latin America to Southeast Asia.

According to preliminary analysis of our data, individuals with MDR-TB experience all four components of stigma: perceived, anticipated, experienced, and internalized. For example, many respondents reported that members of the public regard MDR-TB as highly contagious (generating a fear of infection), universally fatal, and an indicator of HIV infection. Patients we interviewed therefore tried to minimize MDR-TB disclosure to people other than closely trusted confidants. Some individuals conveyed a fear that—if they were to disclose their diagnosis to family, friends, employers, or community members—the disclosure might compromise social support: they could be expelled from their home, lose relationships, or be abandoned, segregated, avoided, or mocked. Another fear is that disclosure might lead to job loss, whether through perceived inability to work or through being fired due to fear of contagion. Respondents reported that there are numerous ways in which MDR-TB treatment can lead others to conclude that individuals have MDR-TB. For example, interactions with the health care system (e.g., daily visits to a clinic), being observed taking their treatment, or medication side effects (including hearing loss or skin discoloration) can lead others to make assumptions about an MDR-TB diagnosis.

These experiences 1) illustrate anticipated and enacted stigma faced by patients with MDR-TB; 2) highlight the linkage of stigma to social justice domains of *agency, respect*, and *association*; and 3) map onto items of the Van Rie stigma scale. Importantly, these qualitative findings also help infer how stigma might be reduced by policies that adopt novel treatment regimens and might destigmatize MDR-TB and/or make undesired disclosure less likely. For example, an all-oral, shorter-course regimen that eliminates the need for prolonged visits to the clinic and/or reduces certain side effects would likely mitigate some of the enacted and anticipated stigma experienced by patients and might ultimately lead to less stigma being attached to MDR-TB in the community more broadly. As a final note, we have used the example of the Van Rie scale to assess stigma in the context of MDR-TB, but this approach is broadly generalizable: for policy related to other diseases, other stigma scales are available and are likely to map similarly onto domains of social justice relevant for those policy considerations.

Using Stigma to Inform Decision Makers of the Potential Social Justice Impacts of Policy Decisions

We have previously applied Bailey and colleagues' social justice framework to suggest how social justice impacts of novel MDR-TB treatment regimens could be presented for decision makers alongside traditional cost-effectiveness considerations, using a variation of multi-criteria decision analysis termed "justice-enhanced cost-effectiveness analysis" (JE-CEA).[13] This technique combines social justice assessments with classical estimates of cost and effectiveness, each attached to different potential outcomes of MDR-TB treatment (e.g., cure, failure, and experience of regimen-limiting toxicity) and their corresponding probabilities. Here, we illustrate how stigma scales such as the Van Rie scale could be used to inform the social justice assessments necessary for JE-CEA and thus help represent social justice considerations in the decision-making process.

Our qualitative data described above illustrates how the standardized scores on the Van Rie scale for both community and patient perspectives toward TB might correlate with the experience of patients, providers, and community members in terms of the impact of MDR-TB on the social justice domains of *agency, association*, and *respect*. Given the availability of these qualitative data suggesting such correlations, one could reasonably administer the Van Rie scale to a group of respondents (patients, providers, and community members), providing explicit instructions to consider standardized vignettes related to MDR-TB when answering questions about "those with TB." These standardized vignettes could follow the format of surveys used to estimate disability weights for the construction of disability-adjusted life years associated with each corresponding state,[20] thus providing an implicit parallel between the assessment of social justice and the assessment of cost-effectiveness. For example, some respondents could be randomized to consider a patient with MDR-TB requiring 9 months of all-oral therapy who experienced a specific toxicity (e.g., skin discoloration from clofazimine[22,23]), whereas others

could be randomized to consider a patient with MDR-TB requiring 20 months of therapy including 8 months of an injectable agent and a different toxicity (e.g., hearing loss from an aminoglycoside[22,24]). Using a standard blocked survey design, a survey of 300 respondents could generate estimates of stigma associated with at least six states for each of two treatments being considered, to within 5 points (out of 50, assuming standard deviations as published by Van Rie and colleagues[21]) on both the community perspectives and patient perspectives scales.[25] This level of precision would likely be sufficient for the stigma/social justice assessment required to perform a JE-CEA (as described below). An alternative approach—that would require independent validation—would include asking respondents to first evaluate stigma associated with one state, then separately ask them to evaluate the likely change in their stigma assessment if different regimens were employed or different outcomes were achieved.

Once this stigma assessment has been performed, one can describe potential policy impacts by assigning probabilities that a given policy decision is "expected to worsen,""may worsen," or is "expected not to worsen" stigma. This assessment of impact on stigma would take a similar approach as the social justice assessment described for JE-CEA, in which similar terms are used to describe the likely impacts of a policy decision on clustering of disadvantages across the domains of *agency, association*, and *respect*.[13] The estimated impacts on stigma (and the probabilities thereof) can then be presented visually to decision makers alongside graphs or tables of estimated cost-effectiveness and any other criteria that might be relevant to the policy decision at hand. In this fashion, policy makers can be informed of the likely social justice implications of MDR-TB treatment policy or any other health policy for which a suitable stigma scale can capture social justice concerns.

Importantly, this approach uses data that can readily be collected using local capacity rather than relying on continued engagement from outside experts. In the example provided here, an initial in-depth assessment was required to demonstrate that stigma (and validated TB stigma scales) might reasonably capture important elements of the social justice impacts of policy decisions related to MDR-TB treatment. Now that this initial assessment has been performed, however, decision makers in individual countries (or subnational regions) need only carry out relatively straightforward assessments of the likely impacts of specific policy options on stigma, as described above. Since a validated TB stigma scale already exists for many contexts, repeat validation of the underlying stigma scale may not be necessary. Adaptation of the stigma scale to reflect specific policy options can likely be done without foreign expertise in many settings—and where such expertise is required, it could likely be obtained through a short-term consultancy (to adapt the scale and pilot the adapted scale) rather than a long-term project (e.g., to implement the evaluation in the full population). The stigma/social justice assessment itself is arguably best carried out by local experts and would need to be presented in an accessible (ideally visual/graphic) format for appropriate interpretation by policy makers, members of civil society, and other laypeople who may not have a technical background.[13] This approach could extend to any other construct (beyond TB stigma) for which a validated scale exists and an initial assessment linking that construct to social justice had been performed. Thus, this example of MDR-TB treatment illustrates how high-quality and relevant social justice assessments can be included alongside cost-effectiveness analyses and any other relevant considerations in high-burden settings, without the need for long-term engagement of foreign expertise.

Conclusion

In summary, the process of evaluating the social justice implications of a potential health policy decision involves the following steps (see Figure 1): 1) Identify a health policy question of potential interest (with at least two alternative potential decisions, e.g., maintaining a standard-course MDR-TB treatment v. switching to a short-course all-oral treatment). 2) Define individual outcomes that are relevant from a social justice perspective and that might be associated with each policy decision (e.g., specific forms of toxicity, cure v. inability to complete treatment, etc.). 3) Perform a single qualitative assessment to link elements of social justice to a construct that has a validated measurement scale (e.g., stigma as described above). 4) Administer the validated instrument to the populations of interest who are most likely to be affected by the policy decision (e.g., patients, providers, and members of communities affected by MDR-TB), asking respondents to assess the various outcomes defined in step 2. 5) Use the results from that survey to attach social justice assessments to each of the individual outcomes from step 2. 6) Assign probabilities, costs, and effectiveness estimates to each of the individual outcomes; in many cases, these can be taken from the existing literature or data (e.g., budgets) available to the decision makers in question.[13] 7) Present both cost-effectiveness and social justice assessments (plus any other important

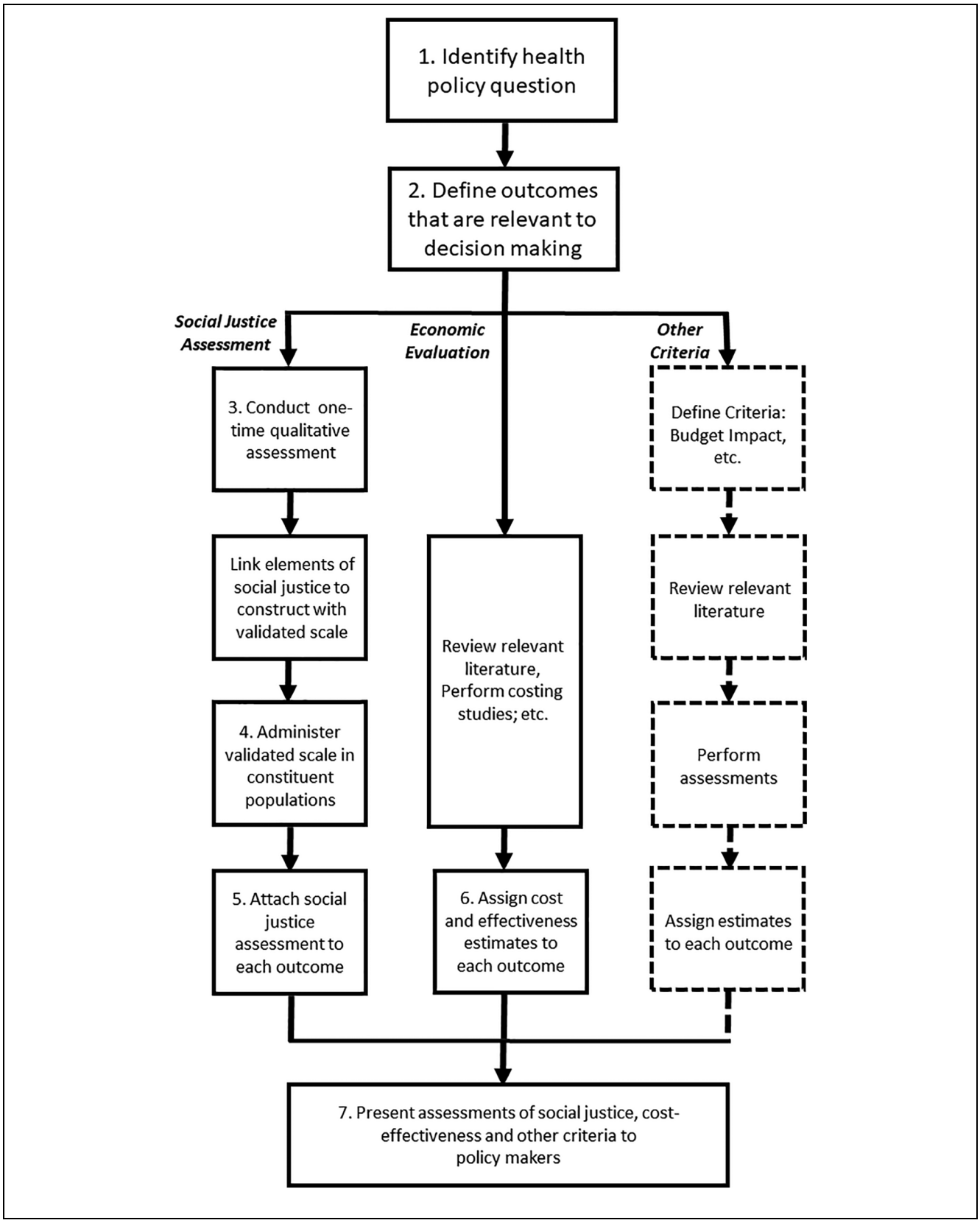

Figure 1 A step-by-step guide for considering social justice in health policy decision making.

decision-making criteria) in tandem to decision makers. We have illustrated here how this could be accomplished in the specific case of a policy decision to switch treatment regimens for MDR-TB, but the above process can be generalized to any policy decision for which specific outcomes can be defined, a validated measurable scale exists for a theoretical construct relevant to social justice, a qualitative assessment can be performed (if necessary) to link social justice considerations to that scale, and a small survey can be carried out to administer that validated scale to constituents of interest. Performing such social justice assessments alongside more traditional evaluations of cost-effectiveness, budget impact, and burden of disease could help represent data-informed considerations of social justice in healthcare decision-making more broadly.

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