# A Systematic Review of Medical Mistrust Measures

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**Abstract**

*Objective*: Medical mistrust is seen as a barrier to health promotion and addressing health disparities among marginalized populations. This study seeks to examine how medical mistrust has been measured as a step toward informing related health promotion efforts.

*Methods:* A systematic review of medical mistrust scales was conducted using four major databases: PubMed, PsycINFO, ERIC, and Communication & Mass Media Complete. Databases were searched using the terms "medical mistrust scale" "medical mistrust" and "medical distrust."

*Results:* The search returned 1595 non-duplicate citations; after inclusion and exclusion criteria were applied, 185 articles were retained and coded. Almost a quarter of studies used a single-item or a few items. Among validated scales the Group-Based Medical Mistrust Scale, Medical Mistrust Index, and Health Care System Distrust Scale were most frequently used. There were important differences among these scales such as the object of mistrust (e.g., system, individual physician) and referent specificity (e.g., group). The measurement of medical mistrust varied by health topic and sample population.

*Conclusion:* These differences in scales and measurement should be considered in the context of intervention goals.

*Practice Implications:* Researchers should be aware of differences in measures and choose appropriate measures for a given research question or intervention.

## A Systematic Review of Medical Mistrust Measures

### 1. Introduction

Medical mistrust—distrust of medical personnel and organizations [1]—has been found to be negatively associated with a variety of health-related behaviors including clinical trial participation, cancer screenings, organ donation, and utilization of healthcare services [2-5]. The recognition of medical mistrust as a health barrier has resulted in calls for strategies to reduce mistrust [6]. However, to achieve this, scholars must first have a clear understanding of medical mistrust and how best to assess it.

Despite an abundance of scholarship on medical mistrust and its recognition as an important factor in advancing health equity, few studies examine measurement of medical mistrust. However, definitional ambiguity surrounding medical mistrust in the literature suggests a systematic review of the conceptualization and measurement of medical mistrust is a critical and missing component of the literature. For instance, some scholars conceptualize medical mistrust as rooted in interethnic group relations and whether respondents perceive medical personnel and health organizations as extensions of the dominant culture [4]. Other scholars conceptualize medical mistrust as separate from perceptions of race-based discrimination [7]. Because scholars might be using the same term (i.e., medical mistrust) to describe different beliefs and because this has implications for health promotion efforts, we sought to examine how scholars are quantitatively measuring medical mistrust.

To our knowledge, no systematic reviews of medical mistrust have been conducted. A systematic review conducted by Ozawa and Sripad in 2013 examined measures of *trust* in the health system [8]. In contrast, our focus is on scales and indices specifically intended to measure

medical *mistrust*. Conceptually, trust and mistrust are related, but distinct concepts. Trust refers to the belief that the trustee (the person or organization in whom faith is placed) will act in the best interests of another (i.e., the truster) [9]. This is different from distrust/mistrust, which is not only predicated on the belief that the trustee will not act in the truster's best interests, but also that they may actively work against them. Recent empirical evidence supports the assertion that trust and mistrust are related, but also have distinct relationships to health beliefs and behavior [10]. Pellowski and colleagues found that although medical mistrust predicted lower medication adherence, neither trust in one's own physician nor trust in one's healthcare provider did. Such findings bolster the argument that trust and mistrust are not simply two sides of the same coin.

### *1.1 Role of Medical Mistrust in Health Outcomes*

Medical mistrust has been cited as a potential social determinant of health, particularly when examining racial or ethnic disparities [11, 12]. There is evidence that medical mistrust is a health barrier and is associated with worse outcomes across many parts of the heath care continuum. For instance, higher reported medical mistrust is associated with unwillingness to participate in clinical research and trials [13-16]. Medical mistrust is also associated with reduced use of preventive services such as routine check-ups and cancer screenings [2, 4, 17-19]. Once individuals are receiving medical care, medical mistrust is related to lower levels of patient satisfaction and treatment adherence [7, 20, 21]. Finally, medical mistrust has been found to be associated with worse general physical and mental health [22].

Although medical mistrust is a barrier to improvement of health generally and cuts across demographic groups, it is especially problematic for marginalized populations that already face health disparities. Groups marginalized in society—due to race, behavior, or some other stigmatized status—are often more likely to be mistrustful about medical institutions and

personnel based on personal experience, or vicarious experiences, including oral histories. These firsthand and secondhand experiences can result in heightened medical mistrust among these groups [23, 24], and in turn contribute to the perpetuation of health disparities. In the U.S., historical legacies include not only the Tuskegee Syphilis Study, but also the medical evaluation of immigrants, medical experimentation on prisoners, and the sterilization of female prisoners [25-28]. As a result, concerns about medical mistrust may originate from distinct historical experiences linked to group identity. For instance, for African Americans, medical mistrust may be tied to concerns about the treatment of their social group and racism.

Given the role of medical mistrust as a barrier to health care and equity and calls by scholars to reduce medical mistrust [6], we investigated how scholars have operationalized and utilized medical mistrust measures in health-related studies. Because addressing medical mistrust as a health barrier depends on a clearly conceptualized understanding of medical mistrust and its operationalization, the current project sought to document the major scales, indices, and items used to quantitatively measure medical mistrust in the literature. In doing so, we provide a nuanced look at which medical mistrust scales are being utilized. We also examine the health topics and racial and ethnic populations in studies examining medical mistrust.

### *1.2 Evaluating Medical Mistrust Measures*

We approached this systematic review with a priori research questions. The questions emerged from research conducted in the context of medical mistrust and organ donation [29], but were suited to a broader systematic review of the medical mistrust literature. The first question was how medical mistrust is assessed in the literature. Medical mistrust may be measured in different ways (e.g., a single item, a few items, subscales, scales with multiple dimensions).

Examining how medical mistrust is measured provides insight as to how scholars are conceptualizing medical mistrust. Thus, we posed the following research questions:

RQ1a: How is medical mistrust quantitatively measured?

RQ1b: What are the primary items or scales that scholars use to measure medical mistrust?

Additionally, medical mistrust is sometimes linked to group membership and that group's position in society. For some scholars, this structural positioning is inherent in some definitions of medical mistrust [4]. This conceptualizes medical mistrust as linked to a group's treatment in society. Groups that have historically or currently experience structural disadvantage are also more likely to face health disparities across a wide range of conditions, including cardiovascular disease and diabetes. Given the historical medical injustices experienced by certain groups (e.g., African Americans, prisoners), it is also important to take inventory of the health contexts and populations examined in conjunction with medical mistrust measures. Thus, we put forth the following research questions:

RQ2: What groups are being assessed for medical mistrust?

RQ3: For what health topics has medical mistrust been assessed?

Next, it is important to determine which objects of medical mistrust are being examined through these measures, particularly with increasing social science focus on multilevel interventional frameworks. Medical mistrust scales could be tapping into individuals' mistrust regarding a particular physician, physicians in general, or medical institutions. Hall and colleagues offer a typology of four potential objects of medical trust; these could also apply to medical mistrust [30]. Objects can exist on both a personal (e.g., physician, medical provider) or

institutional (e.g., hospital, medical system) level, as well as an in regard to an individual (e.g., my physician) or system (e.g., doctors in general). Clarity about which objects of medical mistrust specific scales are measuring is critical to understanding the literature regarding medical mistrust. While some scholars specifically state the object of their measures [7], others may not highlight this aspect of their scales. As with the underlying reasons for distrust, these differences may point to differing focuses in interventions to address medical mistrust. We therefore asked:

RQ4: What objects of medical mistrust are reflected in medical mistrust scales?

Finally, the current, predominant descriptions of medical mistrust also suggest that scales may vary by referent specificity. For instance, Thompson and colleagues include items that ask the respondent about the mistrust of people like themselves, based on their race/ethnicity [4]. In contrast, LaVeist and colleagues' scale asks about whether individuals, generally, are mistrustful of medical institutions [7]. In other words, some scales are oriented towards general mistrust (i.e., people in general), while others emphasize mistrust based on group membership.

RQ5: What are the referents in medical mistrust scales?

## 2. Method

### *2.1 Systematic Literature Search*

A systematic analysis of medical mistrust scales was conducted using four major databases. The PubMed, PsycINFO, ERIC, and Communication and Mass Media Complete databases were searched using the search terms "medical mistrust scale," "medical mistrust," and "medical distrust" and their variations (e.g., "mistrust of medical"). These databases were chosen as they represent domains in which medical mistrust articles may appear: medicine (PubMed),

psychology (PsycINFO), education (which might include medical education; ERIC), and health communication (Communication and Mass Media Compete).

*2.2. Eligibility Criteria*

To be included, articles must have been published prior to August 2016 and available in English. There were no other restrictions on the year of publication. As our study focused on the ways in which medical mistrust has been quantitatively measured, only studies measuring medical mistrust that used a quantitative measure were included. Any article not measuring mistrust was excluded. Commentaries on medical mistrust as well as studies with qualitative analyses finding medical mistrust as an emergent theme were also excluded. Additionally, studies identifying medical mistrust as an emergent latent construct from principle component analysis were excluded as these studies did not set out measure medical mistrust. Figure 1 illustrates the study flow.

*2.3 Data Extraction*

We created a tracking document in Microsoft Excel to collect information relevant to our research questions. A random sample of articles were used to assess inter-coder reliability and authors reached consensus on discrepant items. Krippendorff's alpha ranged from .79 to .84, indicating an acceptable level of reliability. To answer how medical mistrust is measured and the primary items or scales (RQ1a and RQ1b), we coded information about measurement. To determine what groups were being assessed for medical mistrust (RQ2) and the health topics (RQ3), we coded the characteristics regarding health context and sample population. For RQ4, we identified the objects of frequently used medical mistrust scale. In a similar fashion, we

recorded the specificity of the referent in frequently used scales in order to answer RQ5. The categorization of each characteristic is discussed below.

*2.3.1 Measurement.* The scales and indices utilized by studies were assessed by an examination of articles' text and references. In instances in which the items used to measure medical mistrust were unclear, author(s) were contacted when possible. For simplicity, iterations of the same scale were collapsed together. For example, LaVeist, Nickerson, and Bowie (2000)'s medical mistrust measure and the LaVeist, Isaac, and Williams (2009)'s Medical Mistrust Index were coded within the same Medical Mistrust Index category.

*2.3.2 Health context*. Health context was assessed by title and examination of the articles' text. The health context reflected in the article was decided upon based on the health context or behavior with which the study was concerned. Similar health topics were grouped together. For example, organ and tissue donation were combined with blood donation into a single category. Topics appearing five or fewer times were ultimately placed in the "other" category.

*2.3.3 Sample population*. Sample population was first assessed based on whether the sample was taken from a U.S. population or from elsewhere. For U.S. populations, attention was paid to whether the population was delineated based on race. Populations described as African American, Caribbean American, black, or African immigrant were coded as African American/Black. Hispanic/Latinx was used when populations were described as Hispanic, Latino/Latina, or born of a Spanish-speaking country (e.g., Mexican-American). The issue of whether Hispanic/Latinx should be considered a racial category is an unresolved debate and is currently being debated for the 2020 Census. Given work that shows individuals identifying as Hispanic/Latinx consider it to be part of their racial identity [31], it is treated as such for the purposes of this study.

*2.3.4 Object*. The object of the scales was examined utilizing the typology established by Hall and colleagues in 2001. Their typology consists of two dimensions: individual-system and personal-institutional. Based on these dimensions, four types of objects are established. Individual-personal refers to medical personnel with whom an individual has direct contact (e.g., *my* physician). System-personal refers to specific personnel with which an individual may interact (e.g., physician, medical researcher). Individual-institutional describes medical organizations with which individuals are directly involved (e.g., *my* hospital). Finally, system-institutional encompasses medical organizations or institutions that an individual may encounter (e.g., hospitals in general). Qualitative work by Williamson, Reynolds-Tylus, Quick, and Shuck suggests that medical mistrust may extend to other institutions more broadly [29]. In these instances, the object was also coded as system-institutional.

*2.3.5 Referent*. Measures were also examined for the referent used in the scale. Scales may ask about individuals' opinions or beliefs on behalf of themselves (e.g., *you* trust your doctor). Alternatively, questions may also ask about levels of trust held by people in general. Finally, they may be asked whether they believe people belonging to their sociodemographic group should, can, or do trust medical personnel and institutions.

## 3. Results

The search yielded a total of 1595 unique articles. After inclusion and exclusion criteria were applied to results from the database search, 185 unique articles were retained for analysis. A summary table of reviewed articles appears in the Appendix. The articles were published between 1974 and 2016. The medical mistrust measures utilized in these 185 articles were then more closely examined to answer our research questions. The results are discussed in the sections below.

*3.1 Measurement*

The articles revealed that a wide variety of measures and scales have been used to assess medical mistrust. A substantial portion of the medical mistrust measures consisted of single-item measures (n = 20) or a few items that were not part of a previously validated scale (n = **20**). The Group-Based Medical Mistrust Scale (GBMMS) [4], Medical Mistrust Index (MMI) [7], and the Health Care System Distrust Scale (HCSDS) [32] were the most frequently used medical mistrust scales. These three scales accounted for 49% of the medical mistrust measures. Medical mistrust was also assessed in subscales, in the creation of new scales, and other validated scales. Other validated scales included the Corbie-Smith Distrust Index, the Cultural Mistrust Inventory, and the HIV Conspiracy Beliefs [5, 33-35] measure. A list of these measures as well as information about the scales, where applicable, are provided in Table 1.

*3.2 Health Context*

A wide variety of health topics were represented in the 185 articles. Cancer (n = 39), general health (n = 31), organ and blood donation (n = 25), and HIV (n = 20) were the most frequently examined context. Studies about cancer addressed screening and treatment in areas such as breast, prostate, and colorectal cancer. General health encompassed studies that examined medical mistrust as an outcome variable as well as studies that examined the utilization of healthcare services. HIV studies examined individuals who contracted the virus from sexual intercourse as well as injection drug use; these articles also examined willingness to take ART therapy as well as the conspiracy beliefs surrounding HIV and HIV treatments and vaccines. Other contexts explored included genetic testing, organ and blood donation, and vaccination/immunization. A full list of topics appears in Table 2.

*3.3 Sample Population*

Medical mistrust was primarily assessed in a variety of populations in the United States (n = 163). The location of other studies included the United Kingdom, China, Nepal, and Togo. Most studies conducted with U.S. samples examined multiple racial groups including Caucasians (n = 79). Among these studies, few studies, however explicitly reported examining medical mistrust comparatively across racial groups as a study aim. African Americans/Blacks (n = 51) were the second most prevalent sample; this type of sample was present more often than, minority racial groups alone (more than one group that did not include Caucasians, (n = 7)), Hispanic/Latinx (n = 14), American Indian/Native American (n = 3), Asian/Asian American (n = 3), or Caucasian (n = 1) samples. Six studies either did not give details of their study (n = 4) or it was difficult to determine (n = 1).

Additionally, when specifically examining the three most widely used scales, the GBMMS was predominantly administered to African American/Black (n=15) study populations, followed by Hispanic/Latinx (n = 10) and multiple racial groups including Caucasians (n = 10) study populations. The MMI was predominantly administered to African American/Black study populations (n = 13). Finally, the HCSDS has predominantly been utilized when race is not being considered (n = 9). An examination was also conducted to examine whether medical mistrust was measured in marginalized populations, outside of race. Less than a quarter of studies (n = 30) examined medical mistrust in other marginalized populations (e.g., veterans, immigrants, mentally ill, etc.).

*3.4 Object and Referent*

For widely used medical mistrust measures (i.e., GBMMS, MMI, HCSDS), the object(s) and referent specificity of the measures were examined. The object of the GBMMS is primarily system-personal, with one item reflecting system-institutional, and with a group referent. In other words, the scale assesses whether individuals believe members of their group distrust medical workers. The MMI contains items that are both system-institutional and system-personal, and includes both general and personal referents. The MMI asks participants about their beliefs regarding both medical personnel and medical organizations more broadly. This index heavily focuses on a general view (i.e., "*people* should" as opposed to "*I* should"). The HCSDS asks questions about the system-institutional level with both general and personal referent. The scale asks about participants' view about medical organizations and facilities both about people in general, and the participants individually.

## 4. Discussion and Conclusion

### *4.1 Discussion*

A systematic review was conducted to examine a) how medical mistrust has been quantitatively measured in scholarship and b) the content of the most widely used medical mistrust scales. The review revealed that medical mistrust has been widely examined, but that there also is substantial variation in measures used. Three scales are commonly used when measuring medical mistrust: The Group-Based Medical Mistrust Scale, the Medical Mistrust Index, and the Health Care System Distrust Scale. However, we found that nearly a **fifth** (20%) of studies did not measure medical mistrust with scales or indices, but instead used a single item or a few (i.e., 2 or 3) items. Medical mistrust was assessed within a number of health contexts; cancer, general health, and HIV were the most frequently examined topics. Most studies examined populations within the U.S., often using general samples or focusing on those who

identify as African American/Black. Finally, variability was found amongst scales in terms of object and referent. Below, implications and future directions are discussed.

The continued use of single-item and few-item measures of medical mistrust may be particularly problematic. Recent work has suggested that medical mistrust is a complicated construct. Williamson and colleagues found evidence that suggested that medical mistrust is not only about the distrusting physicians, but also the larger systems the medical institutions are situated in (e.g., government) [29]. Additionally, work conducted using the Health Care System Distrust Scale has shown that racial differences only exist for the values subscale, but not the competence subscale [36]. These studies suggest that medical mistrust is a complex and nuanced concept; it would be difficult to capture the nuances and complexities of medical mistrust with one or two items. We would encourage practitioners and health scholars to continue utilizing multiple items and established scales to assess medical mistrust.

For work specifically examining African American health and healthcare behaviors, the widespread use of the Group Based Medical Mistrust Scale is encouraging. For many years, African Americans' medical mistrust was ascribed to knowledge of the Tuskegee Syphilis Study [37, 38]. Since then, scholars have shown that African Americans' medical mistrust extends beyond memories of the Tuskegee Syphilis Study and it does not fully explain medical mistrust [39]. Some have argued that African Americans' mistrust may be rooted in the mistreatment of their group [24]. The use of the Group Based Medical Mistrust Scale may reflect scholars' movement in a direction that aligns with this viewpoint.

Along with African American/Black populations, medical mistrust has also been examined in Hispanic/Latinx populations. This is unsurprising as historically, Hispanic/Latinx have been a marginalized population that suffers from a number of health disparities [40]. While

the focus on these groups is understandable, there are other racial groups in which medical mistrust should be examined. For example, evidence of strained relationships with medical authorities exists for both Asian Americans and American Indians [41, 42]. Additionally, the rise of Islamophobia in the U.S. and Europe suggests that recent history may be breeding an environment in which Arab and Muslim immigrants may also be distrustful of medical personnel and institutions [43-45]. By failing to examine medical mistrust within these populations, we may be missing a critical antecedent to low engagement in positive health behaviors.

There was also a dearth of work examining medical mistrust outside of racially marginalized groups. While examining the sample population, it was apparent that very few studies examined medical mistrust among sexual and gender minority group members. Those that did only examined this group within the context of HIV treatment. Members of this community may also be distrustful or wary of medical personnel and organizations even outside of HIV treatment [46]. Additionally, strained relations have also been shown between medical institutions and immigrants, prisoners, and those labeled mentally ill or disabled [24-26, 47]. With these histories, it is likely that these populations would also experience medical mistrust. Currently, only a small portion of studies examined medical mistrust within these populations. It will be important for scholars and practitioners to be cognizant of and examine medical mistrust within these populations as well.

Cancer, HIV, and general health were the most widely studied health contexts. This intuitively makes sense as cancer is one of the leading causes of death in the U.S. and there are many racial health disparities associated with cancer, HIV, and the utilization of health services [40, 48]. While we by no means intend to imply that these areas should not be examined, it is important to realize there are other areas deserving of attention. Considering the disparities in

mental health care for minority groups [49-51], mental health is one such context in which more attention could be dedicated.

Our results suggest it is important for scholars to choose a medical mistrust measure, not just because it is a "medical mistrust scale," but because of what the scale specifically provides in the context of a given research question or intervention. These varying scales place differential emphasis on certain aspects of medical mistrust; they may vary both on the object of mistrust as well as the referent specificity of the items. For example, if a scholar suspects that individuals believe they should be distrustful of medical organizations choosing to measure mistrust with the Health Care System Distrust Scale or Medical Mistrust Index may be a better choice than the Group Based Medical Mistrust Scale. Although all three scales measure medical mistrust, the Group Based Medical Mistrust Scale examines medical personnel, not organizations. The Health Care System Distrust Scale and Medical Mistrust Index, on the other hand, do examine medical organizations. In some cases, it may be useful for scholars to include multiple scales to understand the locus of distrust and what measures best predict a given outcome. For example, recent work by Pellowski and colleagues found that mistrust measured by GBMMS was related to antiretroviral therapy non-adherence while mistrust measured by MMI was not [10]. Figure 2 provides a decision tree in the hope that it will guide researchers in choosing an appropriate medical mistrust measure.

We also note the definitional ambiguity surrounding mistrust and the conflation of trust and mistrust in the extant literature. Scholars have noted that medical mistrust can be defined in one of two ways a) lack of trust and b) negative beliefs about the intentions of medical personnel or healthcare organizations [32]. Some studies have defined medical mistrust as "lack of trust" [52]. These studies often use a single item to assess both trust and mistrust, asserting that lower

scores equate to mistrust, while higher scores equate to trust. When studies define mistrust as being on the same continuum as trust, the measure does not address the latter conceptualization. An individual can believe his or her interests will not be met (i.e., low levels of trust) without believing than a healthcare provider will actively act against one's best interests (i.e., high levels of distrust). This definitional ambiguity also appears in scale developers' definitions of medical mistrust. Some define it as "lack of agreement with a statement trust" [5], while others recognize that it could also be defined as "negative beliefs that the trustee will act in ways against best interest of the truster" [32]. The use of medical mistrust in a variety of ways suggests a need to clarify the concept of "medical mistrust."

As with any study, there are limitations. First, four major databases were searched; although they are likely to have returned many of the studies measuring medical mistrust, it is possible that some studies were not found and included. However, given the use of cross-disciplinary databases, the number of articles returned, and the amount of overlap between them, we feel confident that we did find many of the studies measuring medical mistrust. Secondly, the current investigation focused solely on studies that measured medical mistrust quantitatively. This only provides a partial picture of how medical mistrust is conceptualized among scholars. Qualitative studies, as well as opinion pieces and conceptual papers, should also be examined to gain a fuller understanding of how medical mistrust is being conceptualized. Future research should address this aspect of medical mistrust literature. Finally, the current investigation examined specific aspects of the scales. The chosen focus does not represent an exhaustive list of how to look at these measures. Additional work may provide other insights into the differences among medical mistrust measures.

### *4.2 Conclusion*

The current study sought to more fully understand the conceptualization and measurement of medical mistrust. Medical mistrust is a widely-cited barrier, but there has been little systematic attention to what scholars are measuring when they measure medical mistrust. The current study highlights the varied use of the term "medical mistrust." It is our hope that this study encourages scholars to more closely examine what is meant by medical mistrust. To create interventions that overcome this barrier, we must first understand and be attuned to the ways in which medical mistrust is conceptualized. The framing of medical mistrust not only shapes our understanding of individuals' perceptions, but also influences how we tackle the barrier (e.g., attention is on attitudes of individuals versus tackling institutional policies).

*4.3 Practice Implications*

Practitioners working with historically marginalized populations will benefit by recognizing the nuances associated with measuring medical mistrust. By choosing measures based on these nuances, researchers can more effectively address this barrier. However, additional study is necessary to better understand medical mistrust. Given the different content of medical mistrust scales and indices highlighted in this study, the next step should be determining the utility of these scales. It is critical for researchers to not only know conceptually which scales they may want to use, but which scales are more highly correlated with or explain more of the variation in health outcomes. Future work should investigate head-to-head tests of medical mistrust scales to provide this information. Understanding these aspects of medical mistrust may lead to more accurate assessment of medical mistrust and ultimately ways to address this barrier.

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Table 1. Measures of Medical Mistrust and Frequency

| Measure | Frequency (%) | # of Items | Dimensions | Setting Developed | Definition of Distrust | Sample Item |
|---|---|---|---|---|---|---|
| **Commonly-used, multi-item scale measures** | | | | | | |
| *Group Based Medical Mistrust Scale* | 44 (23.78) | 12 | 3: Suspicion, Group Disparity, Lack of Support | African American and Latina women who lived, worked, and/or sought healthcare in East Harlem | "tendency to distrust medical systems and personnel believed to represent the dominant culture" p. 210 | "People of my ethnic group cannot trust doctors and health care workers" |
| *Medical Mistrust Index* | 33 (17.84) | 7 | 1 | Random sample of residents in Baltimore City, MD | No specific definition provided, but notes focus on healthcare organizations | "Patients have sometimes been deceived or misled at hospitals" |
| *Health Care Distrust Scale* | 15 (8.11) | 10 | 1 | Adults awaiting jury duty at the Municipal Court of Philadelphia | "absence of trust" and "negative beliefs that trustee will act in ways against best interest of the truster" p. 57<br><br>Notes focus on healthcare system | "Medical experiments can be done on me without my knowing it" |

| | | | | | | |
|---|---|---|---|---|---|---|
| *Revised Health Care System Distrust Scale* | 8 (4.32) | 9 | 2: Values, Competence | Adults seen at primary care or emergency department within Univ. of Pennsylvania Health System | No specific definition provided but notes focus on healthcare system | "The health care system experiments on patients without them knowing" |
| *Cultural Mistrust Inventory* | 6 (3.24) | 48 | 4: Interpersonal Relations, Education and Training, Business and Work, Politics and Law | Black first and second year college males | "tendency to be suspicious of whites" p. 180 | "Whites are usually honest with Blacks" |
| *Corbie-Smith Distrust Index* | 6 (3.24) | 7 | 1 | unclear | "lack of agreement with a statement of trust" p. 2459 | "If your physician wanted you to participate in research, you trust that he or she would fully explain it to you" |
| **Other multi-item scale measures** | 18 (9.73) | | | | | "Research is part of a conspiracy to harm minority groups" |
| **Multiple Scales** | 4 (2.16) | | | | | Items from Trust scale of Patient |

| | | |
|---|---|---|
| | | Care Assessment Survey ("I completely trust doctors' judgments about my medical care") and Medical Mistrust Index ("If a mistake was made in my treatment, doctors would try to hide it from me") |
| **Measures that are part of a scale** | 8 (4.32) | "Certain types of patients get better care from health care organizations than most patients" |
| **Measures with 6-7 items** | 3 (1.62) | Degree participants trusted provider to: offer quality care, know best treatments, provide enough information, keep personal information confidential, treat nonjudgmentally, offer high quality care regardless of insurance status, |

| | | |
|---|---|---|
| | | put needs ahead of research goals |
| **Measures with 2-4 items** | 20 (10.81) | "I trust the health care system" "I think the health care system adequately addresses the needs of gay/bisexual men" |
| **Single item measures** | 20 (10.81) | "It is difficult for me to trust doctors and other health professionals" |

Total differs from 100% due to rounding.

Table 2. Health Contexts and Sample Populations

| Category | Frequency (%) |
|---|---|
| *Health Context* | |
| Cancer | 39 (21.08) |
| Cardiovascular | 7 (3.78) |
| Clinical Research/Trials | 14 (7.57) |
| General | 31 (16.76) |
| Genetic Testing | 7 (3.78) |
| HIV | 20 (10.81) |
| Mental Health | 9 (4.86) |
| None (Scale Validation) | 3 (1.62) |
| Organ and Blood Donation | 25 (13.51) |
| Other[a] | 30 (16.22) |
| *Race*[b] | |
| Not specified | 4 (2.45) |
| Multiple Races (including Caucasian) | 79 (48.47) |
| Multiple Races (minority groups only) | 7 (4.29) |
| Multiple Races (racial groups unclear) | 1 (0.61) |
| African American/Black | 51 (31.29) |
| Hispanic/Latinx | 14 (8.59) |
| American Indian/Native American | 3 (1.84) |
| Asian/Asian American | 3 (1.84) |
| Caucasian | 1 (0.61) |

Total differs from 100% due to rounding.
[a]The other category encompasses all health topics appearing less than 5 times.
[b]Reflects breakdown within U.S. samples (n = 163).

Figure 1. Selection of Review Articles

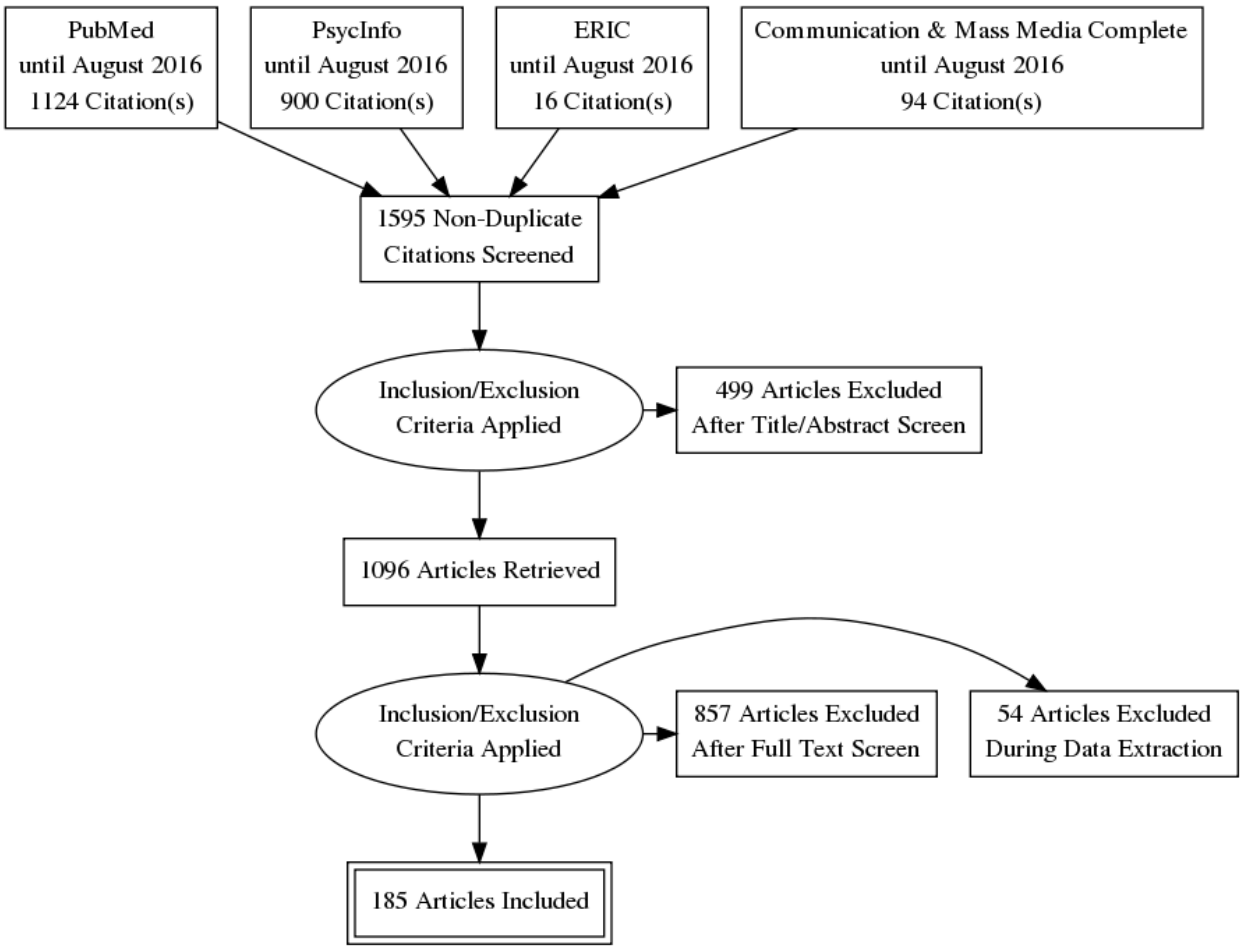

Figure 2. Decision Guide for Choosing a Medical Mistrust Scale