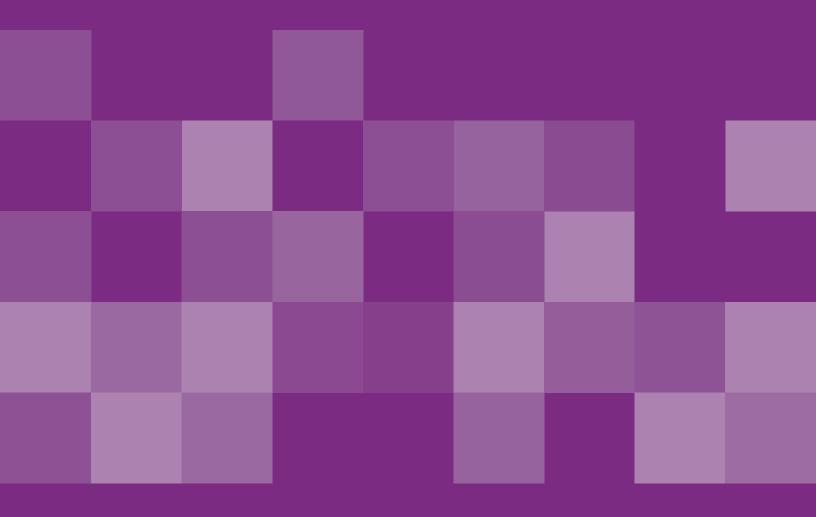
# Measuring Trust: Where are we and where do we need to go?







#### **Background**

Trust is foundational to the delivery of healthcare. Physicians, patients, and organizations rely on one another to perform their responsibilities competently, to be honest in their dealings with one another, and to ensure safety. Trust in each of these relationships is challenged daily. Increasing violence in healthcare settings, predatory billing practices, and discrimination against patients – in addition to the inherent risk of medical care and medical procedures – heightens the need for, and threat to, trust in healthcare. <sup>1-3</sup>

But what is trust, and how do you know whether it's present in a relationship or how resilient it is? While trust is broadly characterized as a willingness to be vulnerable to another in a given context, a recent review of the health services research literature on trust revealed that an operational definition of the term has been, at best, elusive over the past decades. Some studies have used the term to mean a generalized attitude or belief about the perceived trustworthiness of the medical field or of clinicians. Others have developed or relied on dozens of frameworks enumerating at least 20 different attributes of or requirements for a trusting relationship. These attributes include, for example, fidelity or taking the best interest of patients to heart; competency of clinicians or organizations to provide high quality services; and/or being honest and caring in dealings with patients (See **Table 1**). <sup>2</sup>

Table 1: Example attributes of trust<sup>2</sup>

Authenticity Communication Confidentiality Competency Confidence Caring Empathy
Equity
Fidelity
Generalized trust

Honesty/ Integrity
Reliability

Measuring trust has been a challenge for the field, though not for want of effort. There are many survey measures of trust, reviewed in several particularly useful papers. <sup>4-9</sup>

#### Examples include:

Comfort

- Ozawa and Sriprad identified 45 measures of trust across a range of relationships in the health system: trust in clinicians, health systems and organizations, researchers, and others.<sup>4</sup>
- Wilk and Platt conducted a review of measures of physicians
   as the trustor and found only a small handful that assessed
   physician trust in various entities (patients, other clinicians,
   organizations, etc.). These measures varied in how they defined
   and assessed various requirements or attributes of trust such as
   confidence, reliability and competency, reputation, and integrity.<sup>5</sup>

• Benkert and Williamson evaluate measures of mistrust, which they define as the "tendency to distrust medical systems and personnel believed to represent the dominant culture in a given society," and rooted in historical sociopolitical contexts and power that shape contemporary relationships to individuals, communities, institutions, and political structures. The review highlights the need for additional work in measurement and evaluation such as replication studies and greater diversity in study populations.<sup>6</sup>

Three issues have fueled the propagation of trust measures. First is the lack of conceptual clarity across measures. Second, there is a lack of consensus around a single measure or set of measures. And third, trust may operate differently depending on who is trusting whom, and what the context is. Trust in a surgeon may be more reliant on confidence about ability to do the work while trust in a friend may be more about the generosity or fidelity of that person. You may trust the surgeon to perform surgery, but not your friend. While the attributes of trust in these interpersonal relationships may be similar (i.e., trust requires beliefs about competency and fidelity), trust in the medical profession may require different analytic assessments than trust between individuals. These three issues compound one another. The nuance of how trust operates and differs within and across relationships and contexts poses a challenge for standardization or consensus on individual measures. This, in turn, creates a broad range of approaches that make it difficult for a field to converge on clear definitions and concepts.

#### **Purpose of this report**

The purpose of this report is to address the first issue (conceptual clarity). In providing a framework for articulating the meaning of trust with greater specificity, our aim is to inform the dialogue necessary for the second issue (consensus around best measures and best measurement practices), while recognizing that multiple trust measures may be necessary to address the third issue (context dependency). Focusing on both the *substance of trust measurement* and *process* will allow for a more robust set of insights into both the current state of trust in various relationships in the healthcare system, as well as for monitoring change over time and assessing the impact of interventions that aim to rebuild or repair trust.

We provide an overview of how trust has been measured in surveys and provide guidance for those who would like to measure trust. We present questions and recommendations for those evaluating, choosing, or developing measures and provide brief "case study" analyses of some of the key measures of trust in **Appendix A.** Our hope is to enable readers to better articulate *why* they are measuring trust, what key attributes they hope to prioritize in measuring trust, what they hope to gain from measuring trust, and clear expectations about the strengths and weaknesses of any measure they choose.

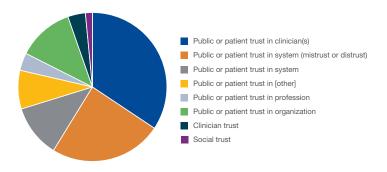
The intended readers for this guide are (1) health system leaders, organizational leaders and others interested in adopting measures at their institutions, (2) health services researchers who may not be focused on the issue of trust as a primary area of expertise, but see it as an important variable or outcome of interest in their work, and (3) those interested in assessing measures to support a convergence of methods and/or processes for choosing how, when, and what aspects of trust are to be measured.

### Trust measures: An analysis of measures and practical implications

Trust is a relational construct, and yet often measured along one axis of a bi-directional dyad: e.g., patient trust in physician, patient trust in health system, physician trust in organization, etc.

Many studies have quantitatively assessed trust in a health care context. As shown in **Figure 1**, most measures of trust assess patient trust in various entities - primarily in clinicians, but also in the medical profession, and in health systems, institutions (government and private), and organizations. Surveys evaluating clinician trust are relatively rare. The disparity in the number of studies examining patients as the trustor, relative to clinicians as trustor, has been found across a variety of reviews of the trust literature. From a feasibility perspective, surveys of patients and the public are easier to conduct.

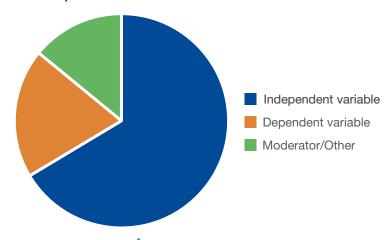
Figure 1. Dyads assessed in survey measures of trust



However, given the relational, dyadic, and dynamic aspects of trust, additional work on trust from the clinician perspective is warranted. Mark Linzer and colleagues are leading the way in assessing clinician trust in organizations, and its relationship to patient trust in their clinician. This measure is described in greater detail as one of the case studies.

Survey research evaluating trust has also generally used trust as an independent variable, rather than a dependent variable (**Figure 2**)  $^2$ . Going forward, researchers have an opportunity to begin to identify predictors of trust, particularly in a time when trust *repair*, *building* and *sustainability* is exigent.

Figure 2. Trust as dependent variable, independent variable, moderator/ other



#### How have different measures been used?

In the form of six brief "case studies" we present examples of trust measures that have been used and cited relatively frequently in the literature. We chose two measures that assess physicians' trust given increasing interest and current initiatives to improve assessment of trust among physicians. Thom et al. developed a measure to assess physicians' trust in their patients, essentially "closing the loop" on the dyad and the nucleus of patient care. We also include Linzer's work on physician trust in organizations (2019, 2021). This is some of the only quantitative research that has taken on the measurement within the physician-organization dyad. Next we examine a measure of patient trust in their clinicians used in a standardized survey of ambulatory care (ACES) as exemplary of this relatively large area of research. The Wake Forest Physician Trust Scale developed by Mark Hall and colleagues is also described. This work also includes work on patient trust beyond the doctor-patient relationship to include the medical profession, insurers, and medical researchers. Trust in the medical profession has for many years been captured by a limited number of questions in public opinion polls. This has allowed for both longitudinal study and comparisons between the U.S. and other countries and is described in the fourth case study. Finally, we include the **medical mistrust** index as an example of a measure that assesses community-level attitudes and beliefs. We chose these measures as a point of departure, and not an endorsement, when considering a survey instrument that you might use in your work.

For each case study we provide a summary of measurement development and use. We provide a description of the instrument and questions (e.g., what attributes are included, how many items, validation procedure), an overview of the studies that have used the measure (research questions, trust as dependent/ independent variable, study population, key findings), and how users might consider its use in the future. Case studies are based on a review of the papers published using these measures.

#### Process of measurement: Where do I start?

Good measurement starts with a clear definition of what's being measured. Given the complex nature of trust as a construct, we propose here a set of frameworks to help articulate the context and specific nature of trust that can then be used to choose or develop a measure of trust.

Starting from a point of clarity about the meaning of trust and the underlying principles of interest should shape the selection or development of measures. This may be accomplished by first considering what is involved in the trustor/trustee relationship and the context of interest. If A trusts B to do X, who is A and who or what is B and X. Next is to consider what underlies the expectation or reliance that B will do X. What will make A feel comfortable being vulnerable to B under these conditions? Is it past experience? Confidence in the ability of B to deliver on a promise? Or is it belief that B is willing to put the needs and interests of A before their own? For example, a patient's expectation that a radiologist can identify a suspicious tumor relies on the belief in that clinician's competency to do so.

Selecting or developing a measure of trust ideally also involves reflection on the process itself. If, for example, one is measuring trust among care team members, members of, representatives of, or people knowledgeable about those teams should be present in articulating expectations among team members. Similarly, issues of inequity and racism may be overlooked if the people involved in issue identification are not those impacted by, or those who rou-

tinely work to address issues of, inequity and racism. Finally, there are questions of feasibility, purpose, and resources that will shape any approach to measuring trust. A rapid measurement may not provide the information one needs, while an in-depth instrument could overburden the study population.

Table 2 below lists six question areas and provides example answers that one might undertake. With these questions answered, a person interested in measuring trust can guide a literature review or evaluate previous surveys to assess alignment. For example, suppose you are on the leadership team of a health organization that has recently had an incident involving patient violence towards medical staff. In the wake of the incident, you make changes to security protocols, but want to know whether your staff trust you (i.e., the organization you represent) in your commitment to workplace safety. Measuring trust begins with articulating who is trusting (your medical staff) whom (you/ your organization) to do what (ensure a safe workplace) (#1-#3 in Table 2). With this in mind, you can then begin to articulate what you mean by trust; for example, you may want to know whether the staff feel they can rely on your ability to enforce protocols and whether your response is perceived to be in the best interests of staff (#4 in Table 2). With a clear definition of the parameters, you can assess your potential biases and blind spots in your assessment and problem definition (#5 in Table 2). Finally, what is the context in which you will conduct your assessment and how do your available time and resources impact your approach (#6 in Table 2).

Table 2. Process of defining trust for survey measurement with example of whether physicians trust their workplace to ensure a safe work environment

1. Who is trusting?	Example: Medical staff (Physicians, nurses, etc.)	
2. In whom?	Example: Organization	
3. For what?	Example: Ensuring a safe workplace	
4. How would you describe trust in this context? Is it reliance? Something else? What are the important attributes (See Table 1 above)? Do the expectations of the trustee and trustor match? What would be the indicators of trust/ mistrust/ distrust in the relationship between #1 and #2?)		
<ul> <li>Examples:</li> <li>Physicians expect hospitals to promote a culture of safety by making it easy to report adverse events</li> <li>Physicians prioritize patients' best interests (fidelity)</li> </ul>		
5. Critical self-reflection: Is the process of measurement design inclusive of diverse perspectives? Are appropriate voices represented? Is there bias in the way questions are framed or how the survey is implemented?		
<ul> <li>6. How much real estate and/or time do you have to commit to trust measurement? What are the implications for the measurement and implementation?</li> <li>Brief questionnaire on job satisfaction survey?</li> <li>Anticipating organizational change?</li> <li>Response to incident?</li> <li>Other?</li> </ul>		

With clarity about definitions and scope of work, one can then go about the exercise of either selecting an existing measure, adapting an existing measure, or developing one's own. It is beyond the scope of this this report to go into the pitfalls and promises of these pathways. However, once a metric has been determined, it is worth reviewing it anew in the context of the above exercises. In other words:

#### Does the measure you use...

- ...evaluate the relationship(s) of interest in the appropriate context?
- ...assess the elements (i.e., requirements, attributes, principles, or meaning) you decided were important?
- ...provide useful information to solve a problem or answer your question of interest?

Will you be able to implement the study?

#### Clarifying purpose, navigating nuance

A number of decision points are likely to arise in setting out to measure trust or trustworthiness – many of them focused on practical issues of time and space on a measurement instrument. Others may be conceptual, arising from the nuance and meaning of specific word choices. For example, in exploring patient trust in clinicians, a survey might ask questions about whether patients expect their physicians want to act in their best interests, whether patients believe clinicians have the ability to act in their best interest or whether clinicians will prioritize the patients' best interests above their own, and above those of the organization. Assessing a patient's overall perception of trust in their clinician (e.g., asking "In general, I trust my primary care physician") may suffice if there is limited space and time, but will not reveal what makes that clinician trusted or not. In general, multiple measures provide a richer set of opportunities for interpretation, but may be constrained by the realities of implementation.

Actionability is often the goal of inquiry – thinking about how the data are going to be used is a key question to consider as a measurement plan is being developed. Surveys are often most helpful for comparing sites and assessing change over time. Qualitative research (interviews or focus groups) might be beneficial – or even preferable – to inform operational changes, impact of current or proposed practices, or assessing culture. As a final check on the measurement plan and steps described above, an iterative consideration of the following questions will help guide the process of

measurement to a fruitful outcome or a better understanding of one's limitations:

- 1. What will I do with the information?
  - (a) What is my (or my organization's) commitment to evaluating trust over time? To building or repairing trust?
- 2. Does the survey question I'm using measure what I'm interested in understanding?
- 3. Will a survey answer the questions I have about trust in my organization?

#### Measuring trust to build trust

The importance of considering issues of equity in trust measurement is not well developed in current research. There has been some critique in scholarship on trust that measuring trust between doctors and patients - or between any two parties - ignores power differentials. The option for a patient to trust a doctor is often eclipsed by a patient's vulnerability and need for medical care. While mistrust and distrust have been explored, there is still work to be done to center community experiences and incorporate the underlying structural aspects of care that include socioeconomic and system-level factors that impact a person's ability to access quality care. A measurement of trust may occlude or reveal these longstanding and entrenched issues. An organization might undertake the work of developing a measure using community-based methods. Engaging in this process could take on the dual role of both building trust and measuring it at the same time, assuming there is organizational commitment to act on findings.

#### What if I'm interested in trustworthiness?

Organizations are frequently interested in their own trustworthiness as a pillar of their mission. Trustworthiness, as distinct from trust, is a property of the trustee, in effect minimizing the relational dynamic of trust and the de facto focus on the trustor present in most work proposing to measure trust. Measuring trustworthiness, then, gets to the question of whether a person or entity is willing to trust, and thus to the important issue of whether a trustee is *deserving* of trust.

When assessing trustworthiness, a similar process of articulating requirements, attributes, and indicators can be a reasonable starting place. The AAMC, for example, has published a set of principles of

trustworthiness that demonstrate how an organization can develop indicators meant to signal that an organization or its governance is deserving of trust.<sup>11</sup> Measurement and evaluation efforts are well positioned if they start with a clear articulation of principles.

## What if I'm interested in something that's not human – like an organization, information, or technology?

Trust is generally conceived as an attribute of interpersonal relationships and experience, and yet we talk about trust in organizations, institutions, government, information, technology, and other entities. These forms of trust may have different operating mechanisms, and may be modeled on interpersonal trust, but should be done with caution. A personal relationship is fundamentally distinct from a relationship with something that is not human. At the same time, one's experience with a technology, for example, its reliability and accuracy shape one's expectations. This process of forming and testing expectations can be analogous for both the personal and non-human subjects of trust. Yet concepts of caring or integrity, which are clearly fundamental to human relationships may apply differently or not at all.<sup>2</sup>

#### **Caveats and disclaimers**

This report is not an endorsement of any specific metric. It is intended to help guide researchers and practitioners in selecting a metric, or to inform the development of a measure tailored to a specific research question. There is a core tension in selecting trust measures that must be acknowledged. On one hand, every relationship and context is unique and therefore potentially deserving of its own, adapted trust measure. On the other hand, the more adaptation and "homegrown" measurement development that occurs, the less the field of trust studies as a whole can integrate, compare and systematically learn from various efforts. Our own view is that, while the issue of contextual variability will remain endemic in research that uses concepts of trust and trustworthiness, standard definitions, methodologies, and a core set of measures can be developed through consensus and peer review.

#### Conclusion

Trust is a critical issue in health care, and should therefore be a key part of health services research studies. Measurement and evaluation tools for this complex construct are sorely needed. The goal of this compendium is to help provide the conceptual clarity for people interested in interrogating trust in a variety of contexts, which can lead to a common language and understanding of what trust means for the wide range of people involved in health systems. It is our hope that readers will use the information here to guide discussion about best measures and best measurement practices.

#### **CASE STUDIES**

- I. Physician trust in patients (Thom, 2011)
- II. Physician trust in organizations (Linzer, 2022)
- III. Patient trust in physicians (ACES)
- IV. Patient trust in physicians (Wake Forest)
- V. Mistrust (Medical Mistrust Index)
- VI. Public trust in medical profession (Various)

#### **Appendix A. CASE STUDIES**

#### I. Physician trust in patients

#### Attributed to

Thom DH, Wong ST, Guzman D, Wu A, Penko J, Miaskowski C, Kushel M. Physician trust in the patient: development and validation of a new measure. The Annals of Family Medicine. 2011 Mar 1;9(2):148-54. <sup>12</sup>

#### **Quick Summary**

- 12 items
- Attributes: Patient role and Respect for boundaries
  - Confidence in integrity, communication, reliability, respect

#### Description

David Thom and colleagues' scale measures physicians' trust in their patients. Their work was guided by a definition of interpersonal trust involving expectations of future behavior with respect to the patient's role. The enrolled population used to validate the measure consisted predominantly of primary care doctors treating unhoused patients with HIV and chronic pain in San Francisco. This patient population and definition of trust led to the metric's focus on normative expectations of patient behavior and non-exploitation of the physician's role and confidence.

At the time of Thom's 2011 publication, at least five patient-trust-in-physician measurement tools had been published, while no converse physician-trust-in-patient measurement tools existed. A tool to measure physician trust in patients is important for its own sake. Physician trust in their patient is vital to gathering relevant treatment information, 13 committing to a care plan, 13 and improving patient perception of and trust in their doctor, and modulating patient behavior. 14 Measuring physicians' trust in their patients is also a necessary component of the dyadic view of the doctor-patient trust relationship. Measuring the physician's side of trust in the patient-physician dyad is crucial to measuring the effects of mutual trust. This mutually reinforcing trust feedback loop is a key motivation of this research, especially in relationships between opioid-prescribing physicians and patients with chronic pain, because patient symptom reports tend to be met with greater skepticism and their

care may involve increased checks on their behavior (i.e. routine urine samples to test for illicit drug use). Thom and colleagues' work was motivated by the potential to contribute a key missing piece of interpersonal patient-physician trust, with the power to affect patient outcomes, care quality, and both physician and patient satisfaction.

The final measure consists of 12 items with a response scale of 1-5 per item (not at all confident-completely confident). Interview and focus group data yielded 21 items. The 21 items were condensed to 18 after pilot feedback from physicians due to extreme language and redundancy. The 18 candidate items were reduced to the 12 final items (listed below) based on factor analysis. The remaining 12-item scale was found to have excellent internal validity (Cronbach alpha = .91).

Six themes were originally derived from analysis of physician participant responses in the semi-structured interview and focus group data; however, initial principal components factor analysis yielded only a 2-factor solution, which were later categorized as pertaining to Patient Role (8 items) and Respect for Boundaries (4 items). The *Patient Role* factor pertains to patients displaying prototypical behaviors of their role in their own care, including providing accurate and complete histories, asking questions, adhering to a treatment plan, and following up. The *Respect for Boundaries* factor pertains to respecting physicians' time and personal boundaries, and avoiding manipulating the physician for personal gain. These two factors, *Patient Role* and *Respect for Boundaries*, were also determined to be their own subscales within the overall *Trust in Patient* scale.

#### **Key Citations**

#### Scale development and validation

Physician focus groups and semi structured interview data from:

Cook K, Kramer R, Thom D, Stepanikova I, Bailey S, Cooper R. Trust and distrust in patient-physician relationships: perceived determinants of high and low trust relationships in managed care settings. In: Kramer R, Cook KS, eds. Trust and Distrust in Organizations: Dilemmas and Approaches. Thousand Oaks, CA: Russell Sage Foundation; 2004:65-98.2 <sup>15</sup>

Stepanikova I, Cook KS, Thom DH, Kramer RM, Mollborn SB. Trust in managed care settings: physicians' perspective. In: Cook KS, Levi M, Hardin R, eds. Whom Can We Trust? How Groups, Networks, and Institutions Make Trust Possible. Thousand Oaks, CA: Russell Sage Foundation; 2009:149-181<sup>16</sup>

Scale piloted in The Pain Study, a 2-year prospective study of pain and opioid use among unhoused adults in San Francisco. <sup>17</sup>

Robertson MJ, Clark RA, Charlebois ED, et al. HIV seroprevalence among homeless and marginally housed adults in San Francisco. Am J Public Health. 2004;94(7):1207-1217.

#### Selected research papers

*Empirical Study*: Wu Q, Jin Z, Wang P. The Relationship Between the Physician-Patient Relationship, Physician Empathy, and Patient Trust. *J Gen Intern Med.* 2022;37(6):1388-1393. doi:10.1007/s11606-021-07008-9<sup>18</sup>

*Empirical Study:* Jepson M, Salisbury C, Ridd MJ, Metcalfe C, Garside L, Barnes RK. The "One in a Million" study: creating a database of UK primary care consultations. *Br J Gen Pract*. 2017;67(658):E345-E351. doi:10.3399/bjgp17X690521<sup>19</sup>

*Empirical Study:* Losin EAR, Anderson SR, Wager TD. Feelings of Clinician-Patient Similarity and Trust Influence Pain: Evidence From Simulated Clinical Interactions. *J Pain Off J Am Pain Soc.* 2017;18(7):787-799. doi:10.1016/j.jpain.2017.02.428<sup>20</sup>

*Empirical Study*: Moskowitz D, Thom DH, Guzman D, Penko J, Miaskowski C, Kushel M. Is Primary Care Providers' Trust in Socially Marginalized Patients Affected by Race? *J Gen Intern Med*. 2011;26(8):846-851. doi:10.1007/s11606-011-1672-2<sup>21</sup>

*Empirical Study*: Goldstein P, Losin EAR, Anderson SR, Schelkun VR, Wager TD. Clinician-Patient Movement Synchrony Mediates Social Group Effects on Interpersonal Trust and Perceived Pain. *J Pain Off J Am Pain Soc.* Published online June 13, 2020. doi:10.1016/j.jpain.2020.03.001<sup>22</sup>

#### Relevant reviews and conceptual papers

*Review*: Ozawa S, Sripad P. How do you measure trust in the health system? A systematic review of the literature. *Soc Sci Med*. 2013;91:10-14. doi:10.1016/j.socscimed.2013.05.005<sup>4</sup>

*Review*: Brennan N, Barnes R, Calnan M, Corrigan O, Dieppe P, Entwistle V. Trust in the health-care provider–patient relationship: a systematic mapping review of the evidence base. *Int J Qual Health Care*. 2013;25(6):682-688. doi:10.1093/intqhc/mzt063<sup>23</sup>

*Review:* LoCurto J, Berg GM. Trust in healthcare settings: Scale development, methods, and preliminary determinants. *SAGE Open Med.* 2016;4:2050312116664224. doi:10.1177/2050312116664224<sup>24</sup>

*Conceptual*: Pellegrini C. Trust: The keystone of the physician-patient relationship. *Bull Am Coll Surg.* 2017;102(1):58-61.<sup>25</sup>

Conceptual: Lloyd EP, Paganini GA, ten Brinke L. Gender Stereotypes Explain Disparities in Pain Care and Inform Equitable Policies. *Policy Insights Behav Brain Sci.* 2020;7(2):198-204. doi:10.1177/2372732220942894<sup>26</sup>

#### **Questions or Items**

12 items; Confidence scale: 1 = not at all confident; 2 = a little confident; 3 = somewhat confident; 4 = mostly confident; 5 = completely confident

Item	Description (Root: "How confident are you that this patient will")
1	Provide all the medical information you need?
2	Let you know when there has been a major change in his or her condition?
3	Tell you about all medications and treatments he or she is using?
4	Understand what you tell him/her?
5	Follow the treatment plan you recommend?
6	Be actively involved in managing his/her condition/problem?
7	Tell you if he/she is not following the treatment plan?
8	Respect your time?
9	Respect personal boundaries?
10	Not make unreasonable demands?
11	Not manipulate the office visit for secondary gain (e.g., for inappropriate disability certification or prescription of controlled substances)?
12	Keep his or her appointments?

<sup>\* (</sup>only final scale items depicted; ultimately deleted candidate items have been removed)

#### II. Physician trust in organizations

#### Attributed to

Mark Linzer, MD, Hannah Neprash, PhD; Roger Brown, PhD, Eric Williams, PhD; Crystal Audi; Sara Poplau; Kriti Prasad; Dhruv Khullar, MD, MPP <sup>10,27</sup>

#### **Quick Summary**

- 5 items
- Attributes: Sense of belonging, loyalty, responsibility, culture of safety, and overall trust

#### Description

Linzer et al used the Healthy Work Place Study to measure clinician trust in their organizations, and to assess the relationship between high and low clinician trust in their organization, and high and low patient trust in their clinicians. The premise of the latter study was that clinicians need to trust organizations and organizational leadership to provide a safe and effective work environment, and patients need to trust their clinicians to deliver high-quality care while addressing their health care needs. Here, we describe the aspect of this work that focused on *clinician trust in their organization*.

Clinician trust in their organization ("organizational trust") was measured using five questions that evaluated the organization's capacity to foster a sense of belonging, loyalty, responsibility to help clinicians with problems, the extent the organization fostered a safety culture by allowing for easy reporting of adverse events, and overall trust. The scale emanates from work by Kralewski in large medical group practices.

Organizational trust was shown to be associated with modifiable organizational attributes such as work control, cohesiveness, emphasis on quality, communication, and values alignment. Trust was also associated with satisfaction, low stress, and commitment to staying in one's practice. A metric of physician-patient trust concordance used as a dependent variable of interest was used to test hypotheses that high trust among both groups (i.e., high physician trust in the organization and high patient trust in their physician) would be associated with favorable organizational culture variables such as emphasis on quality, values alignment, clinician cohesiveness, good communication, and work conditions. Using multilevel regression analysis, trust concordance was associated with emphasis on quality, values alignment, cohesiveness, and communication.

This measure of organizational trust, with clinicians as the trustor, is unique among trust measures.

#### **Key citations**

#### Scale development and validation

Linzer M, Poplau S, Grossman E, et al. A cluster randomized trial of interventions to improve work conditions and clinician burnout in primary care: results from the Healthy Work Place (HWP) study. *J Gen Intern Med.* 2015; 30(8): 1105-1111.<sup>28</sup>

Linzer M, Poplau S, Prasad K, et al; Healthy Work Place Investigators. Characteristics of health care organizations associated with clinician trust: results from the Healthy Work Place study. *JAMA Netw Open.* 2019; 2(6): e196201.<sup>10</sup>

Linzer M, Manwell LB, Williams ES, et al; MEMO (Minimizing Error, Maximizing Outcome) Investigators. Working conditions in primary care: physician reactions and care quality. *Ann Intern Med.* 2009; 151(1): 28-36.<sup>29</sup>

Curoe A, Kralewski J and Kaissi A. Assessing the Cultures of Medical Group Practices. J Am Board Fam Pract. 2003;16:394–8),

Kralewski J, Dowd BE, Kaissi A, Curoe A, Rockwood T. Measuring the culture of medical group practices. *Health Care Manage Rev*. 2005; 30(3): 184-193.<sup>29</sup>

Kao AC, Green DC, Davis NA, Koplan JP, Cleary PD. Patients' trust in their physicians: effects of choice, continuity, and payment method. *J Gen Intern Med.* 1998; 13(10): 681-686<sup>30</sup>

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Schein EH. What you need to know about organizational culture. *Train Dev J.* 1986; 40(1): 30-33.<sup>31</sup>

Kralewski JE, Kaissi A, Dowd BE. Culture as a management tool for medical groups. Published Sep 2, 2008. Accessed Feb 16, 2021. https://www.physicianleaders.org/news/culture-management-tool-medical-groups<sup>32</sup>

Perez HR, Beyrouty M, Bennett K, et al. Chaos in the clinic: characteristics and consequences of practices perceived as chaotic. *J Healthc Qual.* 2017; 39(1): 43-53.<sup>33</sup>

#### **Questions or Items**

Five questions, 4-point scale

To what degree do the following statements reflect the conditions in your group practice? Answered on a scale from 1 to 4, where 1 = not at all, and 4 = to a great extent

- 1. There is a strong sense of belonging to the group
- 2. There is a great deal of organizational loyalty
- There is a strong sense of responsibility to help one of our physicians if he/she has a personal problem
- 4. We encourage the internal reporting of all adverse patient care events
- 5. There is a high degree of organizational trust

Linzer, M., Neprash, H., Brown, R., Williams, E., Audi, C., Poplau, S., Prasad, K., Khullar, D., & Place Investigators, H. W. (2021). Where Trust Flourishes: Perceptions of Clinicians Who Trust Their Organizations and Are Trusted by Their Patients. *Annals of Family Medicine*, *19*(6), 521-526. https://doi.org/10.1370/afm.2732

#### III. Patient trust in physicians

#### Attributed to

Safran DG, Karp M, Coltin K, et al. Measuring Patients' Experiences with Individual Primary Care Physicians. *J Gen Intern Med.* 2006;21(1):13-21. doi:10.1111/j.1525-1497.2005.00311.x<sup>34</sup>

#### **Quick Summary**

- 3 items
- Attributes: confidentiality, confidence, fidelity

#### Description

The ACES tool measures patient experience with respect to individual physicians, practice sites, physician network organizations, and health plans. In addition to trust, ten other components constitute the patient experience: organizational access, visit-based continuity, integration, clinical team, office staff, physician-patient

interactions, communication, whole-person orientation, health promotion, interpersonal treatment, and relationship duration. The trust component concerns the physician-patient interaction only, and thus seems limited to interpersonal trust in one's physician. The three trust items suggest themes of confidentiality/privacy (item 1), competence (item 2), and good will, specifically prioritizing the patient's best interests (item 3). Leading up to the Ambulatory Care Experiences Survey (ACES) was the Primary Care Assessment Survey (PCAS). PCAS included a measure of patient trust – with eight items. Data from PCAS was used to define the three items used in ACES [Safran, personal communication].

Dana Safran et al's 2006 paper<sup>34</sup> was motivated by the increased interest in patient-centered care, popularized by the Institute of Medicine's Crossing the Quality Chasm report. The report sparked a move from assessing quality at the health plan level to the level of individual organizations and patient-provider interactions. The authors sought to create a tool to measure care quality in the primary care outpatient setting, with a particular focus on patient experience. While some other papers had begun this work, this paper is the first with a sufficiently large sample size to generate highly reliable physician-specific information. The primary goal of this paper was to develop a tool to distinguish the influence of individual physicians, practice sites, physician network organizations, and health plans on patient experience, including any interaction effects of the independent variables on patient experience. However, the trust component deals exclusively with interpersonal trust, and is therefore designed to reveal only physician-specific information. This is to say that while the tool generally can provide insight into the relative effect of physician-specific information and health plans on patient experience, the tool cannot reveal the relative effect of physician-specific information and health plans on patient trust.

Two states, California and Massachusetts have used ACES for state-wide measurement and public reporting of patient experiences with physician practices. Both ACES and PCAS have been used extensively in research – including in studies that evaluated the relationship of the measures to both business outcomes (like malpractice risk, loyalty to a practice) and health outcomes (like improved clinical status, adherence to clinical advice). For both PCAS and ACES, studies showed that trust and "whole person orientation to care" were the two strongest correlates or predictors of outcomes (business and health outcomes). [Safran, personal communication].

#### **Trust Items:**

How often did you feel you could tell your personal doctor anything, even things you might not tell anyone else

How often did you feel that your personal doctor had all the information needed to correctly diagnose and treat your health problems

How often did your personal doctor put your best interests first when making recommendations about your care

#### **Key Citations**

Safran DG, Kosinski M, Taira DA, Tarlov AR, Rogers WH, Lieberman N, Ware JE. The Primary Care Assessment Survey: Tests of Data Quality and Measurement Performance. *Medical Care*. 1998. 36 (5):728-739.

Safran DG, Karp M, Coltin K, et al. Measuring Patients' Experiences with Individual Primary Care Physicians. *J Gen Intern Med*. 2006;21(1):13-21. doi:10.1111/j.1525-1497.2005.00311.x<sup>34</sup>

Sikavi, D., & Weseley, A. J. (2017). The relationship between psychosocial factors in the patient–oncologist relationship and quality of care: A study of breast cancer patients. Journal of Psychosocial Oncology, 35(1), 32-46.<sup>35</sup>

Carvajal, D. N., Gioia, D., Mudafort, E. R., Brown, P. B., & Barnet, B. (2017). How can primary care physicians best support contraceptive decision making? A qualitative study exploring the perspectives of Baltimore Latinas. Women's Health Issues, 27(2), 158-166.<sup>36</sup>

Persky, S., De Heer, H. D., McBride, C. M., & Reid, R. J. (2014). The role of weight, race, and health care experiences in care use among young men and women. Obesity, 22(4), 1194-1200.<sup>37</sup>

Sheppard, V. B., Williams, K. P., Wang, J., Shavers, V., & Mandelb-latt, J. S. (2014). An examination of factors associated with health-care discrimination in Latina immigrants: the role of healthcare relationships and language. Journal of the National Medical Association, 106, 15-22.<sup>38</sup>

Fuertes, J. N., Mislowack, A., Bennett, J., Paul, L., Gilbert, T. C., Fontan, G., & Boylan, L. S. (2007). The physician–patient working alliance. Patient education and counseling, 66(1), 29-36.<sup>39</sup>

#### **Specific Items/Questions**

Summary Measure	Item	
Organizational/structural features of care		
Organizational Access	When you needed care for an illness or injury, how often did your personal doctor's office provide care as soon as you needed it	
	When you called your personal doctor's office in the evening or on weekends, how often did you get the help or advice you needed	
	When you scheduled a check-up or routine care, how often did you get an appointment as soon as you needed it	
Visit-based continuity	When you were sick and went to the doctor, how often did you see your personal doctor (not an assistant or partner)	
	When you went for a check-up or routine care, how often did you see your personal doctor (not an assistant or partner)	
Integration	When your personal doctor sent you for a blood test, x-ray, or other test, did someone from your doctor's office follow-up to give you the test results	
	When your personal doctor sent you for a blood test, x-ray, or other test, how often were the results explained to you as clearly as you needed	
	How would you rate the quality of specialists your personal doctor has sent you to	
	How would you rate the help your personal doctor's office gave you in getting the necessary approval for your specialist visits	
	How often did your personal doctor seem informed and up-to-date about the care you received from specialist doctors	
	How would you rate the help your personal doctor gave you in making decisions about the care that specialist(s) recommended for you	
Clinical team	How often did you feel that the other doctors and nurses you saw in your personal doctor's office had all the information they needed to correctly diagnose and treat your health problems	
	How would you rate the care you got from these other doctors and nurses in your personal doctor's office	
Office staff	How often did office staff at your personal doctor's office treat you with courtesy and respect	
	How often were office staff at your personal doctor's office as helpful as you thought they should be	

Physician-patie	Physician-patient interactions	
	How often did your personal doctor explain things in a way that was easy to understand	
	How often did your personal doctor listen carefully to you	
	How often did your personal doctor give you clear instructions about what to do to take care of health problems or symptoms that were bothering you	
	How often did your personal doctor give you clear instructions about what to do if symptoms got worse or came back	
Whole-person orientation	How would you rate your personal doctor's knowledge of your medical history	
	How would you rate your personal doctor's knowledge of your responsibilities at home, work or school	
	How would you rate your personal doctor's knowledge of you as a person, including values and beliefs important to you	
Health promotion	Did your personal doctor give you the help you wanted to reach or maintain a healthy body weight	
	Did your personal doctor talk with you about specific things you could do to improve your health or prevent illness	
	Did your personal doctor give you the help you needed to make changes in your habits or lifestyle that would improve your health or prevent illness	
	Did your personal doctor ever ask you about whether your health makes it hard to do the things you need to do each day (such as at work or home)	
	Did your personal doctor give the attention you felt you needed to your emotional health and well-being	
Interpersonal treatment	How often did your personal doctor treat you with respect	
	How often was your personal doctor caring and kind	
	How often did your personal doctor spend enough time with you	
Patient trust	How often did you feel you could tell your personal doctor anything, even things you might not tell anyone else	
	How often did you feel that your personal doctor had all the information needed to correctly diagnose and treat your health problems	
	How often did your personal doctor put your best interests first when making recommendations about your care	
Relationship duration	How long has this person been your doctor	

#### IV. Patient trust (Wake Forest Scale)

#### Attributed to

Hall MA, Dugan E, Zheng B, Mishra AK. Trust in physicians and medical institutions: what is it, can it be measured, and does it matter?. The Milbank Quarterly. 2001 Dec;79(4):613-39.

#### **Quick Summary**

- Developed measures of patient trust in physicians, researchers, insurance companies
- Conceptual attributes: Competency, fidelity, integrity, confidentiality, global trust

#### Description

Mark Hall and colleagues developed several measures of patient trust in various aspects of medical care: the medical profession, primary care providers, researchers, and insurance companies. Hall et al. synthesize this work in the paper listed above, identifying five cross-cutting attributes across these different relationships: Fidelity (prioritizing the patient's best interests over their own); Compe-

tence (being good at their job and minimizing mistakes), honesty (telling the truth); Confidentiality (being responsible with sensitive information, and Global trust (general sense of trustworthiness). Initial measures of patient trust in their primary care providers captured all five of these dimensions. Trust in insurers addressed the first four. An 11-item scale measuring trust in medical profession captures all but confidentiality (fidelity, competence, honesty, global trust), while trust in researchers assesses opinions about fidelity, honesty, and global trust. The measures underwent several rounds of validation and refinement producing both short forms and long forms of the measures, which generally reduced to one dimensional constructs.

Much of this work, conceptually and empirically, highlights the interdependencies of trust, i.e., trust in physicians is related to trust in medical profession, which is related to trust in insurance companies. In a 2005 synthesis of this work, Hall and colleagues offer a robust analysis of what trust is, the challenges in measuring trust, and the importance of both strong conceptualization as well as empirical analysis.

The Wake Forest trust scales have been shown to be associated with some health behaviors, such as colorectal cancer screening (trust in provider), and retention in HIV care. This work also highlights the importance of what relationship or relationships are being examined and the limitations of how trust operates. For example, in the study of colorectal screening patients, screening adherence was associated with trust in a primary care provider, but not with trust in the medical profession generally. Among patients receiving HIV care, trust was associated with retention in therapy, but not with adherence or enrollment. In another study, issues such as access and quality of interactions in the healthcare setting have an impact on trust in one's individual physician.

The Wake Forest scale has been translated into Spanish,<sup>44</sup> Dutch,<sup>45</sup> French, German, Mandarin Chinese,<sup>46</sup> and several other languages.<sup>47</sup> It has also been validated among different populations, including its use among a variety of age groups <sup>48, 49</sup> and vulnerable populations such as people with HIV, people with cancer, and people from minoritized communities. <sup>50, 51, 42, 52, 41</sup>

#### **Key citations**

#### Scale development and validation

Patient trust in primary care providers

Hall MA, Zheng B, Dugan E, Camacho F, Kidd KE, Mishra A, Balkrishnan R. Measuring patients' trust in their primary care providers. Medical care research and review. 2002 Sep;59(3):293-318.

Patient trust in the medical profession

Hall MA, Camacho F, Dugan E, Balkrishnan R. Trust in the medical profession: conceptual and measurement issues. Health services research. 2002 Oct;37(5):1419-39.

Patient trust in researchers

Hall MA, Camacho F, Lawlor JS, DePuy V, Sugarman J, Weinfurt K. Measuring trust in medical researchers. Medical care. 2006 Nov 1:1048-53.

Patient trust in insurers

Zheng B, Hall MA, Dugan E, Kidd KE, Levine D. Development of a scale to measure patients' trust in health insurers. (Methods). Health services research. 2002 Feb 1;37(1):187-203.

Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. BMC Health Services Research. 2005 Dec;5(1):1-7.

#### Impact (does trust matter?)

Gupta S, Brenner AT, Ratanawongsa N, Inadomi JM. Patient Trust in Physician Influences Colorectal Cancer Screening in Low-Income Patients. American Journal of Preventive Medicine 2014;47:417–23. https://doi.org/10.1016/j.amepre.2014.04.020.

Graham JL, Shahani L, Grimes RM, Hartman C, Giordano TP. The Influence of Trust in Physicians and Trust in the Healthcare System on Linkage, Retention, and Adherence to HIV Care. AIDS Patient Care STDS 2015;29:661–7. https://doi.org/10.1089/apc.2015.0156.

Tanco K, Rhondali W, Park M, Liu D, Bruera E. Predictors of Trust in the Medical Profession among Cancer Patients Receiving Palliative Care: A Preliminary Study. Journal of Palliative Medicine 2016;19:991–4. https://doi.org/10.1089/jpm.2016.0089.

Nguyen AL, Schwei RJ, Zhao Y-Q, Rathouz PJ, Jacobs EA. What Matters When It Comes to Trust in One's Physician: Race/Ethnicity, Sociodemographic Factors, and/or Access to and Experiences with Health Care? Health Equity 2020;4:280–9. https://doi.org/10.1089/heq.2019.0101.

Stults CB, Grov C, Anastos K, Kelvin EA, Patel VV. Characteristics Associated with Trust in and Disclosure of Sexual Behavior to Primary Care Providers Among Gay, Bisexual, and Other Men Who Have Sex with Men in the United States. LGBT Health 2020;7:208–13. https://doi.org/10.1089/lgbt.2019.0214.

#### Languages other than English

Berrios-Rivera JP, Street RL, Garcia Popa-Lisseanu MG, Kallen MA, Richardson MN, Janssen NM, et al. Trust in physicians and elements of the medical interaction in patients with rheumatoid arthritis and systemic lupus erythematosus. Arthritis Rheum. 2006 Jun 15;55(3):385–93. (Spanish)

Bachinger SM, Kolk AM, Smets EMA. Patients' trust in their physician—Psychometric properties of the Dutch version of the "Wake Forest Physician Trust Scale." Patient Educ Couns. 2009 Jul 1;76(1):126–31. (Dutch)

Dong E, Liang Y, Liu W, Du X, Bao Y, Du Z, et al. Construction and validation of a preliminary Chinese version of the Wake Forest Physician Trust Scale. Med Sci Monit. 2014 Jul 5;20:1142–50. (Mandarin)

Huang EC-H, Pu C, Chou Y-J, Huang N. Public Trust in Physicians—Health Care Commodification as a Possible Deteriorating Factor: Cross-sectional Analysis of 23 Countries. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 2018;55. doi:10.1177/0046958018759174 (Various)

#### **Questions or Items**

Shortened measures of patient trust in provider, medical profession, and insurer are listed below. Scale: Strongly Agree (5), Agree (4), Neutral (3), Disagree (2), Strongly Disagree (1). Negatively worded items (marked with \*) are reverse coded. Final scale is the sum of responses for all questions. Trust in physician, Trust in medical profession, and Trust in insurer each have a range of 5-25. Trust in medical professions has a scale of 4-20.

#### Trust in physician<sup>1</sup>

- 1. Sometimes Dr. [INSERT NAME OF DR] cares more about what is convenient for him/her than about your medical needs\*
- 2. Dr. \_ [INSERT NAME OF DR.]\_ is extremely thorough and careful.
- 3. You completely trust Dr.\_ [INSERT NAME OF DR.]'s decisions about which medical treatments are best for you.
- 4. Dr.\_ [INSERT NAME OF DR.]\_\_ is totally honest in telling you about all of the different treatment options available for your condition.
- 5. All in all, you have complete trust in Dr.\_ [INSERT NAME OF DR.]\_.

#### Trust in medical profession<sup>1</sup>

- 1. Sometimes doctors care more about what is convenient for them than about their patients' medical needs.\*
- 2. Doctors are extremely thorough and careful.
- 3. You completely trust doctors' decisions about which medical treatments are best.
- 4. A doctor would never mislead you about anything.
- 5. All in all, you trust doctors completely.

#### Trust in a health insurer<sup>1</sup>

- 1. [INSERT NAME OF HEALTH INSURER] Cares more about saving money than about getting you the treatment you need.\*
- 2. You feel like you need to double check everything [INSERT NAME OF HEALTH INSURER ] does.\*
- 3. You believe [INSERT NAME OF HEALTH INSURER] will pay for everything it is supposed to, even really expensive treatments.
- 4. If you have a question, you think [INSERT NAME OF HEALTH INSURER] will give you a straight answer.
- 5. All in all, you have complete trust in [INSERT INSURER'S NAME].

#### Trust in medical researchers<sup>2</sup>

- 1. Doctors who do medical research care only about what is best for each patient
- 2. Doctors tell their patients everything they need to know about being in a research study
- 3. Medical researchers treat people like "guinea pigs"\*
- 4. I completely trust doctors who do medical research

#### References:

<sup>1</sup>Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. *BMC Health Services Research*. 2005 Dec;5(1):1-7.

<sup>2</sup>Hall MA, Camacho F, Lawlor JS, DePuy V, Sugarman J, Weinfurt K. Measuring trust in medical researchers. Medical care. 2006 Nov 1:1048-53.

#### V. Medical Mistrust Index

#### Attributed to

Thomas LaVeist, Lydia Isaac, Karen Williams

#### **Quick Summary**

- 7 items
- Attributes: fidelity, competency, justice/historical inequity, deceptiveness

#### Description

Benkert et al<sup>6</sup> define Medical Mistrust as the "tendency to distrust medical systems and personnel believed to represent the dominant culture in a given society," rooting mistrust in historical injustice and marginalization. Williamson and Bigman<sup>8</sup> define Medical Mistrust as "distrust of medical personnel and organizations." While the use of mistrust is inconsistent in the literature, there is an understanding of what mistrust is not: Mistrust is not trust, low trust, or no trust. It is also not interpersonal trust.

The Medical Mistrust Index<sup>53</sup> was created to capture mistrust in health care organizations, particularly for people who do not have a regular source of care (i.e., for whom a measure of trust in a personal physician would not apply). Questions in the MMI ask individuals to reflect on the impact of organizations on patients.

The authors of the measure conducted focus groups and literature reviews to generate a set of 17 items for the medical mistrust index. The number of items was reduced to 7 based on principle component analysis. The questions in the MMI address familiar constructs in trust measures, such as fidelity of organizations to the interests of their patients as well as competency of organizations to protect privacy, minimize errors, and "do their jobs." The MMI - unlike other measures - also asks about belief in harm that health care organizations may have committed, based on historical inequity, e.g., "Health care organizations have sometimes done harmful experiments on patients without their knowledge"; "Patients have sometimes been deceived or misled by health care organizations." Fidelity and competency are both positively and negatively framed, thus leading to direct questions about skepticism regarding the competency, good intentions, and trustworthiness of organizations toward their patients. For example: "Sometimes I wonder if health care organizations really know what they are doing," and "When health care organizations make mistakes they usually cover it up". The MMI has been shown to be a predictor of underutilization of services, as well as satisfaction and following medication protocols.

Other measures of mistrust include the Group Based Medical Mistrust Scale<sup>54</sup> and The Health Care Distrust Scale.<sup>55</sup> The Group Based Medical Mistrust Scale evaluates respondents' beliefs and suspicion in health systems and personnel. It also asks directly about discrimination against the respondent's racial or ethnic group. Mistrust measures are often used in research examining attitudes and health behaviors among, predominantly, African American/Black people. Mistrust measures have also been used to study people with stigmatized health conditions such as HIV. While some studies have examined attitudes among Hispanic and Latino groups, other minoritized communities remain largely understudied.<sup>6,8</sup>

When quantitatively (or qualitatively) measuring mistrust, carefully defining and applying a clear definition is important. In Benkert et al's review, they note that even in the same study, researchers using one of the medical mistrust measures (e.g., MMI), often conflate mistrust and low trust in their conceptual models, analysis, and interpretation. They also note the need for broader and consistent applications of the MMI and other measures among different study populations to better assess and understand the validity of the measures. Williamson and Bigman review mistrust measures and provide a useful synthesis of the primary measures of mistrust, noting the challenges in defining the construct and validating measures for diverse populations. Like other measures of trust, MMI and other measures have more often been used to predict outcomes rather than as a dependent variable of interest.

The MMI has been used in 33 studies<sup>8</sup>. Recently (2019) the MMI was translated and validated in Spanish.<sup>56,57</sup>

#### **Key Citations**

#### Scale development and validation

LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. Health services research. 2009 Dec;44(6):2093-105.<sup>53</sup>

#### **Spanish translation**

Sheppard VB, Huei-Yu Wang J, Hurtado-de-Mendoza A, Sutton AL, LaVeist TA. Psychometric properties of the Medical Mistrust Index (MMI) in Latina immigrants. Behavioral Medicine. 2019 Apr 3;45(2):128-33.<sup>56</sup>

Sheppard VB, Wang JH, Hurtado-de-Mendoza A, Sutton AL, LaVeist TA. Medical Mistrust Index--Spanish Version. Behavioral Medicine.<sup>58</sup>

#### Selected research papers

LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. Medical Care Research and Review. 2000 Nov;57(1\_suppl):146-61.<sup>59</sup>

Kinlock BL, Parker LJ, Bowie JV, Howard DL, LaVeist TA, Thorpe Jr RJ. High levels of medical mistrust are associated with low quality of life among black and white men with prostate cancer.<sup>60</sup>

Sheppard VB, Mays D, Tercyak KP, LaVeist T. Medical mistrust influences black women's level of engagement in BRCA1/2 genetic counseling and testing. Journal of the National Medical Association. 2013 Mar 1;105(1):17-22.<sup>38</sup>

#### **Questions or Items**

7 items, Scale: "strongly disagree," "disagree," "agree," and "strongly agree."

- (1) You'd better be cautious when dealing with health care organizations
- (2) Patients have sometimes been deceived or misled by health care organizations
- (3) When health care organizations make mistakes they usually cover it up
- (4) Health care organizations have sometimes done harmful experiments on patients without their knowledge
- (5) Health care organizations don't always keep your information totally private
- (6) Sometimes I wonder if health care organizations really know what they are doing
- (7) Mistakes are common in health care organizations

LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. Health services research. 2009 Dec;44(6):2093-105.

#### Similar measures

#### Group-based Medical Mistrust Scale

Thompson HS, Valdimarsdottir HB, Winkel G, Jandorf L, Redd W. The Group-Based Medical Mistrust Scale: psychometric properties and association with breast cancer screening. Preventive medicine. 2004 Feb 1;38(2):209-18.<sup>54</sup>

Shelton RC, Winkel G, Davis SN, Roberts N, Valdimarsdottir H, Hall SJ, Thompson HS. Validation of the group-based medical mistrust scale among urban black men. Journal of General Internal Medicine. 2010 Jun;25(6):549-55.

Buseh A, Kelber S, Millon-Underwood S, Stevens P, Townsend L. Knowledge, group-based medical mistrust, future expectations, and perceived disadvantages of medical genetic testing: perspectives of Black African immigrants/refugees. Public Health Genomics. 2014;17(1):33-42.<sup>62</sup>

#### Health Care System Distrust Scale

Rose A, Peters N, Shea JA, Armstrong K. Development and testing of the health care system distrust scale. Journal of general internal medicine. 2004 Jan;19(1):57-63.<sup>55</sup>

Shea JA, Micco E, Dean LT, McMurphy S, Schwartz JS, Armstrong K. Development of a revised health care system distrust scale. Journal of general internal medicine. 2008 Jun;23(6):727-32.<sup>63</sup>

Armstrong K, Putt M, Halbert CH, Grande D, Schwartz JS, Liao K, Marcus N, Demeter MB, Shea JA. Prior experiences of racial discrimination and racial differences in health care system distrust. Medical care. 2013 Feb 1:144-50.64

#### Relevant reviews

Williamson LD, Bigman CA. A systematic review of medical mistrust measures. Patient education and counseling. 2018 Oct 1;101(10):1786-94.8

Benkert R, Cuevas A, Thompson HS, Dove-Medows E, Knuckles D. Ubiquitous yet unclear: a systematic review of medical mistrust. Behavioral Medicine. 2019 Apr 3;45(2):86-101.<sup>6</sup>

#### VI. Public trust in medicine/ institutions

#### Attributed to

Robert Blendon

Various: include Gallup Poll, Harris Interactive Poll, General Social Survey, Robert Wood Johnson Foundation

#### **Quick Summary**

- 1 item each
- Attributes: General trustworthiness, confidence, honesty ethics

#### Description

An overwhelming number of surveys on trust and health are cross-sectional. One exception to this is a handful of public opinion polls that have tracked public attitudes about medicine as an institution over time. In these surveys trust in medicine is often asked in terms of **confidence** or generalized trust in the institution or profession of medicine or healthcare. More recently, trust in public health has been assessed, given the salience of the COVID-19 pandemic and increased awareness and recognition of public health. Questionnaires and data are often freely available.

Examples of public opinion surveys include the **Gallup Poll**, which has asked about confidence in the medical system from 1993 to today (with a variant asked in 1975 and 1977). The **General Social Survey**, which has been ongoing for over fifty years (since 1972), has asked about confidence in the institution of medicine in ways similar (and thus comparable) to the **Harris Interactive Poll**, which assesses confidence in leadership in (i.e., "the people running") medicine for decades. Across these polls, public confidence has declined overall.<sup>65</sup> More recently, the Robert Wood Johnson Foundation published a report on trust in various health and public health entities. Robert Blendon and colleagues have published

a handful of papers that analyze and reflect on this longitudinal assessment or contextualize the findings of national surveys in the U.S. as compared to other countries.<sup>65-67</sup>

Using a single item to measure trust is appealingly simple, and there are many who suggest more questions are not necessarily better when measuring trust. However, when assessing general trust or confidence in a system, particularly the fragmented and heterogeneous system in the U.S., it can be difficult to know precisely what is being captured by the responses. Mark Hall noted in his reflections on trust measurement that trust in institutions is generally lower than interpersonal trust, most likely because of the human connection with a personal physician. The relative benefits and challenges of the single-item measures of trust in the medical profession circle back to the question of whether and how the measurement matches the research question, definition of trust, and desired outcome of measuring trust.

#### **Key citations**

#### Selected research papers

Blendon RJ, Benson JM, Hero JO. Public trust in physicians—US medicine in international perspective. N Engl J Med. 2014 Oct 23;371(17):1570-2.66

Blendon RJ, Benson JM. Trust in Medicine, the Health System & Public Health. Daedalus. 2022 Nov 15;151(4):67-82.<sup>67</sup>

Blendon RJ, Benson JM. Americans' views on health policy: a fifty-year historical perspective. Health Affairs. 2001 Mar;20(2):33-46.  $^{65}$ 

Hall MA. Researching medical trust in the United States. Journal of health organization and management. 2006 Sep 1;20(5):456-67. <sup>68</sup>

#### **Questions or Items**

1 item, Likert Scale (various)

#### Gallup

1. Please tell me how you would rate the honesty and ethical standards of people in these different fields -- very high, high, average, low or very low?

[medical doctors]

[nurses]

[pharmacists]

https://news.gallup.com/poll/1654/Honesty-Ethics-Professions.aspx

I am going to read you a list of institutions in American society. Please tell me how much confidence you have in each one – a great deal, quite a lot, some, or very little?

[the medical system]

[the healthcare system]

https://news.gallup.com/poll/171710/public-faith-congress-falls-again-hits-historic-low.aspx

#### **Harris Interactive**

"As far as people in charge of running (READ EACH ITEM) are concerned, would you say you have a great deal of confidence, only some confidence, or hardly any confidence at all in them?" [Medicine]

https://www.prnewswire.com/news-releases/confidence-in-congress-stays-at-lowest-point-in-almost-fifty-years-152253655.html

#### **General Social Survey**

I am going to name some institutions in this country. As far as the people running these institutions are concerned, would you say you have a great deal of confidence, only some confidence, or hardly any confidence at all in them? [Medicine]

#### **Robert Wood Johnson Foundation**

Q5. In terms of recommendations made to improve health, how much do you trust the recommendations of each of the following groups? Do you trust them a great deal, quite a lot, somewhat, not very much, or not at all for recommendations they make to improve health?

[Nurses]

[Healthcare workers you know]

[Doctors]

[The American Cancer Society]

[The CDC]

[The American Red Cross]

[Your local health department]

[Your state health department]

[The Surgeon General]

[Your friends or family]

[The NIH]

[The FDA]

[The National Academy of Medicine]

[The federal Department of Health and Human services]

https://www.rwjf.org/en/insights/our-research/2021/05/the-publics-perspective-on-the-united-states-public-health-system.html

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- Taylor LA, Nong P, Platt J. Fifty Years of Trust Research in Health Care: A Synthetic Review. The Milbank Quarterly 2023;101:126–78. https://doi. org/10.1111/1468-0009.12598.
- Zink A, Taylor LA, Nong P, Platt J, Yarkony A. The Overlooked Role Of Physician Trust In Patients. Health Affairs Forefront n.d. https://doi. org/10.1377/forefront.20221123.351289.
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