

INTRODUCTION

Trust in Health Care and Science: *Toward Common Ground on Key Concepts*

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The Covid-19 pandemic has brought trust to the fore of public consciousness. Trust has always been a critical ingredient in the delivery of health services and the acceptance of public health guidance, but emergency conditions during the pandemic highlighted the social consequences when trust is weak or absent. Trust is critical for facilitating coordination among the public, health care delivery organizations, public health authorities, other government entities, and local community organizations, and it is crucial in affecting a population's willingness to accept expert opinion. Where trust was waning or absent during the pandemic, helpful masks went unworn, usable hospital beds sat empty, and effective vaccines sat on shelves.

There were many sociopolitical issues at play in the breakdown of trust during the pandemic, including political polarization, the rapid spread of disinformation and the disparate impact of the pandemic on high- and low-income populations. Each of these factors likely increased distrust and weakened the nation's ability to manage the pandemic. A lack of trust was not the only sociopolitical obstacle to the United States' Covid vaccination and response effort, but it surely inhibited some people from following public health guidance and seeking medical care.

The pandemic coincided with an invigorated national conversation about the pursuit of health equity, which also depends on trust. These twin catalysts spurred an uptick in academic and private-sector interest in the concept of trust. Between 2008 and 2018, the average number of records indexed in PubMed (a search engine for biomedical literature maintained by the United States National Library of Medicine) with “trust*” in the title was 527. In 2019, the year the pandemic began, 801 papers were indexed with “trust*” in the title, rising to 986 in 2020, the year George Floyd was murdered. Since then, the figure has continued to climb, to 1,223 in 2021 and to 1,370 in 2022.

Beyond the academic discourse, the private sector has responded by focusing its own form of attention on trust. Press Ganey, which conducts surveys of patients for health care organizations, released an e-book in July of 2020 titled *Building Workforce Trust: Lessons from COVID-19*.¹ Deloitte, a consulting firm, followed suit in 2021 with a lengthy article titled “Rebuilding Trust in Health Care: What Do Consumers Want—and Need—Organizations to Do?”² In summer 2022, CVS Health sent out the report *Health Trends: Trust in Health Care*, with the blurb “Public opinion has hit a critical moment. Where has trust eroded—and what can be done to build it back?”³ And in spring of 2023, approximately seventy organizations focused on health care, public health, and biomedical research formed The Coalition for Trust in Health and Science to identify and share resources and best practices.⁴

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We take trust to be a social good with intrinsic value that society has a crucial interest in cultivating. Given the rapid rise in efforts to increase trust, especially in the health care industry and in research settings, our goal has been to examine the ethical permissibility of certain ways of cultivating trust.

The uptick in attention is well-founded. Covid suddenly shook portions of the public's trust in health care, but trust in health care has also been on a decades-long slide—along with trust in virtually every other major American institution. As Robert Blendon and John Benson recently described in an excellent review in *Daedalus*, public polling shows that the share of the public expressing a great deal of confidence in “the people in charge of running” medicine fell from 73 percent in 1966 to 57 percent in 1973 and eventually to 34 percent in 2012.⁵ Views of the medical system do not appear to be dramatically different from views of its leaders. From 1993 to 2019, Gallup asked members of the U.S. public about the nation's medical system, and, during that period, only 34 percent to 44 percent of the respondents expressed a great deal or quite a lot of confidence in it.⁶ Low levels of trust in abstract conceptions of U.S. health care—“people in charge of running” it and “the system”—rise when the party being asked about becomes more concrete. For example, 14 percent of people say they trust hospitals completely, and 58 percent say they trust hospitals somewhat. Doctors and nurses enjoy still higher levels of trust—with nursing being the most trusted profession in America for at least the past fifteen years.⁷ Yet it is unclear how long these professions can maintain high trust ratings when embedded in, and increasingly employed by, organizations and systems with such low trust ratings.

It can be easy to tire of reading about trust's role in the pursuit of health. Insights can all bleed together at the highest level of generalization: trust is essential, without it virtually no health organization can persist, and yet the roots of mistrust are multifaceted. What one reads about trust at more operational levels can feel scattershot. One empirical study measures trust as a physician's reported belief about a manager's competence; another conceptualizes it as a patient's adherence to medication.

A recent review articulates the limits and gaps in fifty years' worth of literature on trust in health care.⁸ A key challenge has been that little energy has been put toward studying trust as an outcome. Instead, most studies in health policy and services have treated trust as an input, or predictor, and then examined what outcomes or behaviors it predicts. For example, studies often measure levels

of trust to predict whether patients will adhere to medication regimens or appointment schedules. Even where the empirical literature offers clear insight into what might influence measures of trust, the literature tends to be uncritical about when trust-building efforts might amount to manipulation. Moreover, different approaches to measuring trust have made it difficult, if not impossible, to conduct meta-analyses or to synthesize key insights across papers, even within the confines of a specific trustor-trustee relationship.

This special report contributes to the available literature by responding to some of these challenges. In commissioning these essays, we have aimed to generate actionable insights that can help to advance an area of research that we believe has been historically stymied by conceptual confusion and a long-standing insistence on treating trust as a purely instrumental good. Instead, we take trust to be a social good with intrinsic value that society has a crucial interest in cultivating. Further, given the rapid rise in efforts to increase trust, especially in the health care industry and in research settings, our goal has been to examine the ethical permissibility of certain ways of cultivating trust, thereby adding a needed critical perspective to ongoing academic and popular discussions on the topic.

The challenge of multiple, and some would say competing, definitions and frameworks for trust may be reproduced in this essay set more than it is solved. In developing the special report, we began with a definition of trust as a willingness to be vulnerable to the risk of exploitation, an abstract definition that sidesteps some disagreements about whether trust is an attitude or behavior yet still accords with widely accepted accounts of trust. That said, efforts to study this phenomenon in specific empirical contexts or to deploy it in service of better understanding specific relationships within health care and public health required authors to add additional qualifiers and descriptions. Indeed, the essays in this volume build upon a trust literature that is intensely pluralist in its conceptions and definitions of trust. As a result, what began as a loose but unified concept became unavoidably tailored to authors' purposes. The set is therefore more akin to a stained-glass window than a single pane. The essays exhibit some diversity of thought with

regard to key concepts while also exhibiting a significant degree of convergence. Viewing them as a collection reveals a series of insights that are meant to help clarify scholarly understanding of trust and trustworthiness and inform the development of future interventions aimed at improving both qualities.

Trust versus trustworthiness. The first insight on which authors converged is related to terminology, which has long plagued the trust literature in health care. Authors are clear, and generally quite careful, in distinguishing “trust” from “trustworthiness.” However, the two terms can be confused, and indeed become tautological, when “trustworthiness” is defined as the quality of *being* trusted. The confusion is clarified when “trustworthiness” is defined more precisely as the quality of being *deserving of* trust. Jonathan H. Marks makes this distinction explicit in his essay as he differentiates institutional actions that aim to improve patients’ perceptions of the organization—thereby increasing trust—from those that reform the internal workings of the organization—and thereby make it more *trustworthy*.⁹ Laura Specker Sullivan draws a similar contrast, suggesting that trust is the belief in the possession of praiseworthy traits and trustworthiness is the possession of those traits.¹⁰

Distinguishing these terms helps one identify two very different kinds of problems related to trust, both of which warrant scholarly attention. Generally, discussions about “trust problems” in health care assume that the problem takes the following form: people are not trusting trustworthy actors (see the bottom left quadrant of table 1). But as several authors in this special report make clear, there are good reasons to doubt the trustworthiness of some health care actors—and therefore not to trust them. In fact, it may be the case that people are *too* trusting of health care actors in cases in which trustworthiness should be in question (see the top right quadrant of the table). Identifying which type of problem is most relevant in a given scenario yields distinct intervention strategies. Where the problem is that people fail to trust trustworthy actors, interventions aimed at improving transparency and generally bringing trustors and trustees into closer contact may be warranted. However, where the problem is that people trust untrustworthy actors too much, suggested interventions may more appropriately be substantive reforms to improve the trustee’s trustworthiness.

Competence—and something more. The second insight is that perceptions of a trustee’s competence—or their ability to successfully complete the task on which a trustor is relying—is necessary but not sufficient for trust. Competence is at the heart of much of the literature on trust in health care. Many prior authors have suggested that interprofessional trust is premised wholly on adjudications of technical competence, and some have called for more transparency about quality metrics to increase the public’s trust in health care. The essays in this set continue that emphasis, calling out the importance of physicians to protect patient safety,¹¹ of algorithms capable of appropriately identifying candidates for organ transplants,¹² and of the U.S. Food and Drug Administration (FDA) to competently evaluate safety and efficacy data.¹³ But the essays are also clear that decisions to trust are about more than competence.

Precisely what this “something more” is, and is called, is a matter of some divergence among the authors. Patrick T. Smith and Jill K. Sonke describe “competence, care, and attention to context” as features of trustworthiness,¹⁴ while Michelle M. Chau and colleagues take “honesty, competence, . . . good communication” and a commitment to maintaining confidentiality to be the relevant trustee traits.¹⁵ The additional terms used in trust frameworks generally indicate that a trustee plans to deploy their competence in service of the “right” intention, which could be by following a set of prescribed rules, doing what is ethically right, or placing a trustor’s interest in front of their own.

Reciprocal nature of trust. The third insight is that trust in any given relationship is reciprocal—meaning, the more I believe that you trust me, the more willing I am to trust you. Indeed, Thomas H. Lee, Senem Guney, and Deirdre E. Mylod’s essay includes this quotation from a patient, describing the basis for their high level of trust: “Dr. [X] . . . validated my knowledge of the disease and trusted that I know my body.”¹⁶ The essay by Rachel Grob, Stacy Van Gorp, and Jane Alice Evered underscores that even a concept that appears unitary—trust in oneself—is influenced by one’s belief that they are trusted by others.¹⁷ Feeling doubted by health care professionals can lead patients to mistrust not only those professionals but also their own instincts and experiences. At a more macro level, Kenneth R. Fleischmann’s essay elucidates how interactions between

Table 1.
Trust and Trustworthiness

	Trustworthy actors	Untrustworthy actors
People trust	No problem	Social problem
People do not trust	Social problem	No problem

At both national and local levels, those responsible for speaking with the public and with patients must develop more sophisticated ways to communicate about complex and ever-changing scientific matters.

the U.S. government and the public entered something of a trust doom loop during the Covid-19 pandemic—with government officials failing to trust the public to digest complexity and the public losing trust in officials' willingness to tell the truth.¹⁸

This reciprocity is conceptually elegant but can create a chicken-and-egg problem for those looking to practically intervene in a low-trust or mistrustful relationship. In the real world, neither party in a mistrustful relationship is likely eager to extend themselves. Both see it as foolhardy to act as if trust exists where it has been clearly absent. Without a marked change in trustworthiness, trust repair is a rarity. Either the parties need to coordinate simultaneous action—each making themselves vulnerable to the risk of exploitation—or one party needs to move first, without assurance from the other that their trust will be reciprocated.

While some of the essays emphasize this reciprocity, the matter deserves careful consideration in future work. For example, the question remains as to what kinds of vulnerability physicians and other clinicians face in their relationships with patients, their employers, or the public. Without this vulnerability clarified, the precise nature of professionals' trust remains murky. Moreover, it is not settled whether physicians, or clinicians generally, owe patients their trust as a matter of professional responsibility. Together, the essays highlight just how vexing the reciprocal nature of trust can be and the centrality of improving trustworthiness rather than simply aiming to increase trust. We return to this point later.

Interpersonal as well as structural forces. The fourth point of convergence is that people's trust is influenced by both their own, lived experiences with a trustee and larger, structural forces that influence individuals' biases, defaults, and normative expectations. What appear to be freestanding decisions about whether to trust actually take place in what Specker Sullivan describes as trust "climates."¹⁹

This insight comes with good news and bad news for health care and public health actors seeking to be trusted. The good news is that people's interactions with health care providers and organizations can indeed be changed in ways that are likely to improve trust. Lee and colleagues point to several physician behaviors that may improve patient trust,²⁰ and Mark Schlesinger and Rachel Grob point to others at the organizational level.²¹ These papers align

with a growing empirical literature on how health care providers and organizations can change their own behaviors to increase others' trust in them. The American Board of Internal Medicine Foundation's Building Trust initiative has been a key propeller of this line of research.²²

The bad news is that there is a natural limit to how much a single health actor's behavior is likely to influence others' trust in them. Although it is empowering to see that changes in behavior can improve trust, it should be humbling to recognize how multifactoral a decision to trust can be. When the public's trust in institutions is declining across the board, for instance, the health care system will suffer negative spillover effects. When only 20 percent of people report that they trust health care administrators all or most of the time, even the most trustworthy health care administrator will face an uphill climb. When a society is riddled with systemic racism, predominantly White institutions will be met with reasonable skepticism by communities and patients of color, and when conspiracy theories about public officials abound, trust in experts will likely recede. In developing an account of climates of trust, Specker Sullivan describes how these kinds of social factors influence individual decisions to trust in clinical contexts. In so doing, she provides a new framework for conceptualizing the relationship between socioeconomic and political determinants of trust and individual behaviors.

Ethics of trust building. The authors were consistent about a zone of ethical impermissibility called out most clearly by Marks: it is wrong for a health care actor to seek to win others' trust when it knows itself to be undeserving of said trust. He writes that, where a perception of mistrust "is justified, efforts to change that perception without first addressing the underlying problem are inherently deceptive."²³ In effect, Marks is arguing against efforts to coax people into the top right quadrant in table 1. Jody Platt and Susan Goold echo Marks, asserting that "institutions operating in health care and public health need to both earn and deserve trust."²⁴ Melissa Creary and Lynette Hammond Gerido's essay affirms this normative assessment, arguing that health care institutions that "perform" trustworthiness—meaning that they seek to appear trustworthy without having undertaken substantive racial equity reforms—are deserving of critique.²⁵

Health care professionals and health care organizations that seek to build trust should shift their focus from measuring how patients perceive them to considering how they act toward and communicate with patients.

These essays provide an opportunity for readers to recognize problems that can arise when trust is treated simply as an instrumental goal. In working on this special report, we have been struck by the absence of studies that attempt to define and measure trustworthiness. It seems that the research focus in health policy and health services has been disproportionately on patients and their attendant attitudes, when researchers might learn as much, or more, by studying the behaviors of institutions and providers.

Our essay set also brings attention to another research trend, a set of empirical studies that are designed to produce insight as to the kind of behaviors, symbols, or signals that patients trust. These studies create the potential for ethical dilemmas. A natural implication will be for health care providers and organizations to adopt identified practices and signs, regardless of whether they are reliable indicators of the organizations' actual trustworthiness. Doing so may well increase patients' trust, but the essays herein make clear that getting better at persuasive messaging that is not reflective of reality transgresses an ethical boundary. Not only is such careful messaging or performative behavior unethical, but such acts can also work against one's own interests in the longer term: when we are careless in how we court others' trust, we risk self-defeat.

Building and borrowing trust. The essays reveal a sixth insight, which is that there are at least two (and likely more) strategies for building trust. The first strategy, illuminated in essays like Paige Nong's on trust in data systems and Leah Z. Rand and colleagues' on the FDA, is to directly attempt to improve trustors' impressions of the trustee.²⁶ Where the trustee is trustworthy, this may be primarily a communications task, but where the trustee is less so, this may require substantive reform. Both these efforts can be time and resource intensive—as was painfully revealed during the pandemic.

The second strategy, which is highlighted in Smith and Sonke's essay as well as that by Chau and colleagues, is for a health care institution to "borrow" trust by aligning itself with someone who is trusted, such as an artist or a community-based organization.²⁷ The build and borrow strategies can be undertaken in tandem, but they build trust through distinct mechanisms.

The borrowing strategy, in particular, raises ethical questions for readers' consideration. The first set of concerns are for the health care actors looking to increase trust in themselves. Creary and Gerido caution readers about the risks when health systems perform trustworthiness without actually reforming themselves to be deserving. Under what conditions is borrowing trust by aligning oneself with a trusted actor performative in the way these authors caution against?

The second set of normative concerns are for the parties whose trust is being borrowed. For instance, Smith and Sonke suggest that artists risk losing hard-earned trust if they appear to be co-opted or become complicit with injustices perpetrated by health care actors. One can imagine similar risks for community-based organizations that appear too cozy with mistrusted health systems. How much, if at all, should trusted actors permit themselves to be "used" in service of building health care actors' trust?

Communicating the contingent and iterative nature of science. Arthur L. Caplan's essay in this special report references a quotation by Francis Collins, director of the National Institutes of Health from 2009 through 2021, who acknowledged late in the Covid-19 pandemic that he had not appropriately prepared the public for the reality that the information he provided to them would likely change each time he gave an update.²⁸ Looking at the organizational level, Schlesinger and Grob's essay on health system handling of medical error makes a parallel point. "In our assessment," the authors state, "the only way to reduce the corrosive effects of medical mishaps on trust is to increase public awareness of how frequently adverse medical events occur."²⁹ If the potential to be wrong sets science apart from ideology or religion, then a trustee's willingness to admit to being wrong is key to any scientific endeavor's integrity.

This clear call for revealing the provisional nature of science and communicating it well will no doubt place practitioners looking to build trust in an uncomfortable posture. In the face of waning trust, it is natural to want to convey competence at all costs—and as Lee and colleagues and Nong point out in their essays in this special report and others do in the broader literature on trust in health care,

competence is central to trustworthiness. At both national and local levels, these essays make clear, those responsible for speaking with the public and with patients must develop more sophisticated ways to communicate about complex and ever-changing scientific matters.

In looking across these themes and the essay set as a whole, we are struck by the importance of embracing humility in several respects. First, health care professionals and health care organizations that seek to build trust should first look inward to determine how trustworthy their policies and practices are and how they can be improved. This kind of humility requires these professionals and organizations to shift their focus from measuring how patients perceive them to considering how they act toward and communicate with patients. Second, embracing humility calls on health care professionals and organizations that measure their patients' trust to understand what is behind those patient assessments. These professionals and organizations must ask, what matters to patients and how can we be responsive to that? Finally, humility may be particularly challenging for experts whose professional identity is premised on demonstrations of competence. The reality is that individual clinicians and health care organizations must walk a fine line: earning trust requires a demonstration of competence—to assure people they will not be harmed due to a lack of ability—and humility—to assure people they will not be exploited due to hubris.

The essays in this special report provide conceptual and theoretical insights intended to guide both future empirical research on trust and trustworthiness and new policies and practices. For members of the health care and scientific community, developing into trustworthy professionals and committing to the creation of trustworthy organizations and institutions are complex tasks worthy of great effort. This development and commitment lay the groundwork not only for improved health care quality and improved population health but also for many other positive societal spillovers. Indeed, at this time when trust in science and health care has been weighed down by societal factors beyond the control of health care leaders and scientists, intentional efforts to build this trust can buoy one of our society's most critically important civic projects.

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