



# SUMMARY PAPER

*By Timothy Lynch, JD*

 FOUNDATION  
*Reframing  
Trust*

A PATH TO ADDRESS MISINFORMATION

Leaders from across health care gathered for the 2023 ABIM Foundation Forum to learn more about historical causes of mistrust and skepticism of science, to develop a deeper understanding of the connection between mistrust and misinformation, and to identify strategies that stakeholders across the system could employ to build trustworthiness and reduce the impact of medical misinformation. During three days of meetings, participants heard from a range of experts and worked together to develop new ideas for addressing the lack of trust that has undermined American medicine and the clinician-patient relationship.

## INTRODUCING THE TOPIC

Richard Baron, MD, the president and CEO of the American Board of Internal Medicine (ABIM) and the ABIM Foundation, welcomed participants and introduced the topic of the meeting. “We believe that one of the reasons that misinformation has such traction is a lack of trust in institutions, which creates fertile ground for misinformation to take hold,” he said.

Dr. Baron discussed some of the developments that arose from the 2022 Forum, which also addressed misinformation. This included the formation of the [Coalition for Trust in Health & Science](#), which has brought together more than 65 organizations to address misinformation; the creation of a grant program to fund educational programs to help physicians deal with uncertainty; and the development by the [Public Good Projects](#) of a newsletter to keep clinicians apprised of trending topics in misinformation and advise them about how to respond when patients raise them.



(left to right) Jackie Judd, David Coleman, MD, and Richard Baron, MD

Dr. Baron noted the larger context in which the meeting was taking place, referencing the recent order from a Federal District Court preventing federal officials from contacting social media companies about misinformation. David Coleman, MD, the chair of the ABIM Foundation and a research professor and interim director at the Yale Center for Clinical Investigation, agreed that the environment facing health care leaders and those seeking to combat misinformation had fundamentally changed.

Dr. Coleman said that he did not understand all of the drivers of mistrust and misinformation. He said he needed to employ more humility in thinking about patients and the information they bring to the clinical encounter, and that clinicians need to seek to understand other points of view even as many in society are increasingly uninterested in doing so.

## PATIENT AND TRAINEE PERSPECTIVES

Participants then watched a video that featured four patients who had lost trust in the health care system:

- Lydia had not vaccinated her children after members of an online breastfeeding group—which she turned to after her physician dismissed her concerns about struggling to breastfeed—shared unfounded beliefs about vaccines; she changed her mind and had her children vaccinated after the COVID-19 pandemic began and she researched vaccine safety on her own.
- Hannah had a series of childhood illnesses that her physicians could not diagnose. She was eventually diagnosed with Crohn’s disease, but her surgeon dismissed her suggestion that she also had endometriosis

and was skeptical of her desire to allow her gynecologist to observe her Crohn's surgery. As it happened, Hannah did have severe endometriosis.

- Sondra lost trust after her primary care office repeatedly failed to make needed referrals, a failure that caused her to wonder whether the staff might have paid more attention to her requests if she were not a woman of color. The office staff acknowledged their mistakes and apologized.
- Sherrie incurred extraordinary medical costs after surgery to remove her colon; she went into septic shock after a second related procedure, followed by months in the hospital and subsequent surgeries. She owed more than \$850,000, declared bankruptcy and pays about \$900 per month toward her medical debt, and cannot afford recommended follow-up visits with her gastroenterologist.



(left to right) Mercy Adetoye, MD, Meg Gaines, JD, and Jeanne Marrazzo, MD

After participants watched the video, a panel discussed their takeaways. Meg Gaines, JD, distinguished clinical professor of law emerita at the University of Wisconsin-Madison, said that people in the professions believe they need to apply their own expertise, but that it would have made an extraordinary difference if someone had asked those patients, 'You have expertise – how can I help?' She stressed the importance of clinicians trusting in patients.

Mercy Adetoye, MD, clinical assistant professor at the University of Michigan, noted that Lydia had a background in science but was still pushed into the 'anti-vax' movement because she lacked a sense of community with her clinician; she also pointed out that Lydia obtained some misinformation from a pediatrician's book, spotlighting the need for regulating the profession.

Jeanne Marrazzo, MD, director, Division of Infectious Diseases at the University of Alabama at Birmingham School of Medicine, drew a few lessons from the videos. First, she stressed the importance of first encounters with patients, particularly when they are feeling vulnerable, such as in Hannah's story about being dismissed as anxious as a child. Second, she thought much of the disconnects in the videos involved differences between provider and patient, such as gender differences. "It's harder for us to understand people who aren't like us, sometimes despite our best efforts," she said.

Ms. Gaines noted how the goals of care differ when patients have a role in setting them. "High-performing teams wouldn't dream of leaving the station without a shared understanding of the goals," she said. Susan Edgman-Levitan, the executive director of the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital, said that Massachusetts' requirement that hospitals have patient/family advisors has helped instill a "stronger sense of respect for what patients go through to manage their own illnesses."

During the question and answer session, Giselle Corbie, MD, the Kenan Distinguished Professor, Departments of Social Medicine and Medicine at the University of North Carolina School of Medicine, said that she saw herself in the clinicians with no time in the scenarios described in the patient videos. She attributed the care delivered to those patients to structural issues such as burnout and a lack of time to spend with patients. Gwen Darien, executive vice president for patient advocacy at the National Patient Advocate Foundation, reiterated the need for clinicians to trust patients, and suggested that doing so would help avoid burnout by creating trusting, open and curious relationships.

## RESIDENTS AND STUDENTS

A resident and three medical students—winners of an essay contest cosponsored by the ABIM Foundation and the American Medical Student Association—then delivered speeches based on [their essays](#), in which they had reflected on an experience where they or someone they knew received, shared or acted upon misinformation in a health care setting.



(left to right) Elina Kurkurina, Molly Fessler, MD, Meher Kalkat, Isra Hasnain and Marianne M. Green, MD

Meher Kalkat, a third-year medical student at Johns Hopkins School of Medicine, told the story of her slow process of attempting to build trust with a patient who was a refugee. This patient would not agree to receive a recommended root canal for fear that the government would use his removed teeth to falsely accuse him of a crime, as he said that physicians turned patients over to the police in the country he had fled. “At first I thought I could win everyone over,” she said. “Now I sit beside them, listen without judgment, and wonder about what led them to their beliefs.”

Molly Fessler, MD, a resident at Duke University School of Medicine, described a patient living in a tent who exhibited COVID-19 symptoms but who believed that COVID-19 was a hoax and declined to be tested. “It felt like a provocation,” she said. “But infrequently do we understand the allure [of misinformation], how it may make sense to those for whom the system hasn’t worked.” She called for asking questions and seeking understanding. “We must see one another before we try to change one another,” she said.

Elina Kurkurina, a second-year medical student at the Frank H. Netter School of Medicine at Quinnipiac University, talked about a young patient who had inhaled dust and debris on a construction project. He read online that vigorous exercise would help alleviate his condition, but instead it exacerbated his asthma. “Misinformation and misinterpretation often go hand in hand,” she said. “Caring for vulnerable patients requires trust, comfort, and thoughtful communication to help alleviate the[ir] anxiety.”

Isra Hasnain, a fourth-year medical student at the University of Chicago Pritzker School of Medicine, told the story of a patient in her 80s who did not want medication for her anxiety. She had read on Facebook that such medication would make her crazy. The attending physician patiently walked the patient through medications she already took to treat physical conditions and how she had not hesitated to take them, and persuaded her that she should not feel any differently about treating mental health issues. “Patient hesitation offers the opportunity to probe deeper,” she said. “With each conversation, not only would trust grow but also patient empowerment.”

These medical students and residents were named as the inaugural class of Wolfson Scholars, in recognition of Daniel Wolfson, MHSA, the executive vice president and chief operating officer of the ABIM Foundation from 2002–2023, who has been a leader in recognizing the importance of mentoring and advancing the careers of young physicians.

## THE SYSTEM PERSPECTIVE

A panel of executives at health systems discussed their thoughts about misinformation and trust.

Odette Bolano, RN, CEO, West Region, Trinity Health – Idaho | Oregon | California, said that patients have been left in the middle as health care has become a big business, left uncertain about who they can trust. Eric Wei, MD, senior vice president and chief quality officer at NYC Health + Hospitals (NYCHH), noted that employees in health systems are just as susceptible to misinformation as the general public. He said he falsely assumed that staff at



(left to right) Odette Bolano, RN, Eric Wei, MD, David Baker, MD, and Fred Cerise, MD

hard-hit hospitals in New York City would be eager to receive the COVID-19 vaccine after their experiences early in the pandemic. He described the resistance of staff at Harlem Hospital to be vaccinated, even under threat of losing their jobs. Among other things, he attributed the trust issues that NYCHH faced to “decades of mistrust” between leaders and employees.

Moderator Fred Cerise, MD, the president and CEO of Parkland Health & Hospital System, asked the panelists how they were building trust. Ms. Bolano

described her system’s patient advisory council and physician advisory councils, and how system leaders regularly visited patients before pandemic-era restrictions were established. Dr. Wei said that patients can tell whether hospital staff cares about them and listens to their concerns, and told a story about moving vending machines in one hospital so that children who were not allowed to eat did not have to pass by them. “You need full tanks of empathy,” he said. “If you’re burned out, patients can tell.”

Dr. Wei described how a medical student who worked for NYCHH during a gap year between his MS3 and MS4 years developed a workshop on viruses and vaccines and met with every unvaccinated employee at Harlem Hospital. He said this student was “a more credible messenger than the CEO” and convinced many to get the vaccine voluntarily and at least improved the outlook of those who only received it to save their jobs.

David Baker, MD, MPH, executive vice president at the Joint Commission (JC), described seeking the views of the American Society of Anesthesiologists about the JC requirements that anesthesiologists viewed as the most problematic. The JC developed responses and changed a standard that it could not support. “Even before cultural humility comes plain old humility,” he said. He also described holding weekly town halls during the pandemic, offering that “transparency is the best way to build trust.”

Don Wesson, MD, former chair of ABIM and the ABIM Foundation, described his father’s reaction when he learned in 1974 that he planned to attend Washington University Medical School in St. Louis – “Son, have they seen you?” Dr. Wesson, who is Black, said every system where he had practiced had refused to treat Black patients at an earlier point in their history. In light of this history, he asked, “How can systems gain community trust?”

Dr. Wei said that NYCHH had created the Medical Opportunities for Students and Aspiring Inclusive Candidates (MOSAIC) system to try to increase its number of physicians from under-represented groups. The program includes mentoring for high school students and expenses-paid rotations at NYCHH for medical students, in partnership with Historically Black Colleges and Universities and Puerto Rico Medical School. Dr. Baker recounted how he previously worked at the Grady Hospital in Atlanta and patients would refer to ‘the Gradys,’ from when there were two segregated hospitals. “I believe in trust and reconciliation,” he said. “You have to tell the truth first before you can get trust. There’s no substitute for saying we’re sorry, you were wronged in the past.”

## PRESIDENT’S LECTURE: A HISTORICAL PERSPECTIVE

Dr. Baron introduced the two historians who served as President’s Lecturers for this year’s Forum: Lewis Grossman, JD, and Sophia Rosenfeld, PhD.

Professor Rosenfeld said that physicians are traditionally considered trustworthy in two distinct ways: their ways of knowing things (their training and scientific expertise) and their moral disposition (they have their patients’ best

interests in mind). In other words, she said, they have both epistemic and moral authority. She argued that both of those qualities are in crisis, not only from the spread of misinformation but also from longstanding mistrust that is increasing in some communities under new pressures, and that is subjecting physicians to a kind of skepticism that is unfamiliar for many of them.

To understand this, she said, one needs to take a longer view than just the last few years. She described a lengthy history of arguments about who gets to say what counts as truth and on what grounds, especially in democratic societies, and of mistrust of science and its practitioners. She attributed this skepticism toward science partly to the power of scientific elites, particularly in the 20th and early 21st centuries, when both natural and social scientists became increasingly central to the operations of government.

Professor Rosenfeld explained that under the democratic ideal, the people are sovereign; knowledge elites help make democracy work but in conjunction with ordinary people. As knowledge elites have become more powerful, however, they have grown further from people's ordinary experience and ways of knowing things. Their specialized language and often obscure findings have primed non-experts to be skeptical and feel they are not receiving 'straight information.' The pandemic exacerbated this trend, with changes in public health messaging coming across more like a failure than the process of medicine working its way through a problem.

As the power of knowledge elites has grown, she noted, the world has also become more democratic and less hierarchical. At best, ordinary people can provide a corrective to elite knowledge, as demonstrated by the role of citizen movements during the AIDS crisis and the civil rights movement. At worst, ordinary people can decide to separate themselves entirely from knowledge elites and reject the moral and epistemic authority of organized medicine. These people—found more often at present on the political right than the left, though this is historically variable—may rely more on common sense or faith or unvetted sources on the internet, making them part of the larger conflict between expertise and populism that we are seeing today. The trend is enabled by social media, the deregulation of mainstream media, political pandering from those who trade in disinformation for political gain, and basic inequalities.

Professor Rosenfeld suggested that breaking this dynamic would require thinking at a variety of levels: the deeply intimate and personal level of the specific encounter; the world of information and media more broadly (e.g., universities, public health messaging); and tackling some of the larger educational and cultural, as well as economic, inequalities that make people believe they are operating in totally different worlds from one another.

"I have bad news for you," Professor Grossman began. "You are the medical establishment and much of the country views you as godless despots." He said this level of suspicion was actually a reversion to the historical norm, not just a reaction to the pandemic. He said that we had recently emerged from an atypical period during the 1940s–70s, in which the public held institutions in general, and medicine and science in particular, in high regard.

Throughout American history, he said, a broad swath of the population has believed that people have the right to choose their medical treatments without government interference or compulsion, and that the medical establishment had controlled regulatory mechanisms in a way to squelch the people's choices and increase their own wealth and power. These beliefs have been rooted in notions of bodily autonomy, freedom of conscience and opinion, and in freedom of religion. "Until surprisingly recently, therapeutic effectiveness has been viewed as a matter of opinion and not fact, and this continues to be the case in much of the population," Grossman said.



(left to right) Sophia Rosenfeld, PhD, Lewis Grossman, JD, and Richard Baron, MD

The arguments supporting this concept of ‘medical freedom’ have derived not only from concepts of individual economic liberty (e.g., ‘Why shouldn’t we be able to use our own money to pay for whatever treatment we want?’) but also an important anti-monopolist strand that, for example, questions medical and pharmaceutical licensing as features of a medical trust enforced by a government that has been captured by elites.



Lewis Grossman, JD

Professor Grossman said that although misinformation is often conflated with concepts such as propaganda and deceit, most opponents of traditional medicine have believed what they are saying. Portraying such people as dupes and victims, he suggested, is unlikely to sway their views. He also noted that opponents of orthodox medicine generally do not simply reject the idea of science, but instead often use scientific vocabulary and quasi-scientific studies to support their conclusions. Professor Rosenfeld noted that opponents “use tropes of science in part because appeals only to religion don’t go very far now.”

In response to a question about statistics, Professor Grossman noted that statistics are about averages, but we live in an individual-focused society and a common refrain of medical libertarianism is “I am not a statistic.” “Probability can be profoundly unsatisfying for individuals, particularly those with serious or fatal conditions,” he said.



Sophia Rosenfeld, PhD

Dr. Baron noted Dr. Rosenfeld’s focus on the concepts of “common knowledge” and “common sense.” She said that common sense repeatedly arises as a kind of antidote to other ways of knowing. It serves as a pushback against formalized ways of knowing, such as using the occurrence of a snowstorm to “refute” global warming. However, she said, much of what counts as knowledge today, including vaccines, runs counter to common sense. She described how thinkers from Thomas Jefferson in the 18th century to John Rawls in the 20th have argued that the meeting of science and common sense is fundamental to democracy. By dismissing ‘common sense,’ even when it seems wrong, then, she said we “fail at the experiment that is democratic knowledge production.”

Asked about the causes of the “Golden Age” of trust, Professor Grossman noted that trust in medicine rises and falls along with trust in other established institutions, but that medical accomplishments such as the invention of antibiotics and the polio vaccine did generate great public trust. He also said that the 1970s were the ‘fulcrum decade’ in which trust declined, and he referenced the women’s health movement and the growing recognition that under-represented populations weren’t benefiting from medical advancements as much as whites as major contributors to this decline.

Dr. Baron asked how the medical profession should respond to arguments that it is protecting its own economic interests through licensing and other means. Professor Grossman recommended embracing the aspirations of other medical professionals, such as nurse practitioners, to be essential providers of care.

Jeanne Marrazzo, MD, said that skeptics had argued that the scientific community was making it up as it went along during the pandemic, while the community believed it was following the scientific method. Professor Grossman agreed that the science had established a set of indisputable facts about COVID-19 through standard scientific processes. However, he argued that many of the controversial decisions (e.g., masking, closing schools) were policy decisions, not just scientific ones, which he said is also true of the drug approval process. As policy decisions, they are open to challenge. Professor Rosenfeld also pointed to the conflicting advice about masking early in the pandemic, and the feeling that the guidance was based on factors beyond science, such as preserving supplies for medical personnel

and avoiding scaring the public. “It ate away at people’s basic trust,” she said. “I wish there was more leveling with the public, and less treating the public as children themselves.”

Participants then discussed their takeaways from the President’s Lecture. Highlights included:

- democracy thrives when the knowledge elite and lay people interact, and we have to bring together ‘book learning’ and lived experience to do the best for patients;
- the need to develop new ways to build a sense of community across society;
- the importance of being honest about and accountable for where we have created harm, and taking concrete steps to rebuild relationships with our communities;
- the recognition of how regrettably rarely the word ‘humility’ is used in the medical context;
- and, the need to focus on the potential consequences of the financialization of health care, especially through the increased role of private equity in the health sector.

## REFLECTIONS ON THE DAY

Alan Weil, JD, MPP, the editor-in-chief of Health Affairs, offered three themes he took from the first day: (1) the pendulum between expertise and populism; (2) difficult conversations that even participants might prefer to avoid, such as the resource gap between public institutions like NYCHH and institutions owned by private equity; and (3) the distinction between misinformation and disinformation, and the potentially fertile ground of thinking in terms of patients’ misunderstanding or misinterpreting clinical recommendations.



(left to right) Vineet Arora, MD, and Alan Weil, JD, MPP

Vineet Arora, MD, the dean for medical education at the University of Chicago Pritzker School of Medicine, discussed the patient stories, which she said were reminders of how we may have fallen short of earning trust and connecting with ordinary people. She said the medical students and residents’ amazing stories were a bright spot, but she asked how we might make these bright spots our default expectation instead of praiseworthy outliers.

Dr. Arora noted the tension between our desire for patient-centeredness and empowerment through shared decision making and our feelings about patients asking questions about ivermectin and COVID-19 vaccines. She also wondered if the medical profession is further away from ordinary people than ever before, with medical students overwhelming coming from the wealthiest segments of society.

Mr. Weil said that from a policy perspective, the focus on the historical origins of mistrust for historically (and often presently) marginalized populations offered a narrative and potential approach. Misinformation had affected many people outside those categories, however, and the approach to this broader group was unclear. He pointed out that the First Amendment places significant limits on policies to address the misinformation problem.

Dr. Arora stressed the value of finding ways to coach people to get good information; she said this was a current area of study for many, and encouraged the uptake of promising approaches. She also said that clinician burnout remains a serious problem, with many clinicians debating their futures. In this climate, relying on health care workers to debunk misinformation in their spare time will not be a good model.



## BEGINNING DAY TWO

Jackie Judd, a former journalist and communications consultant, opened the meeting's second day with some words of optimism. She said that she felt unexpectedly hopeful about the health care community coalescing around the complex problems that were discussed on Day One. For her part, she said that while she previously thought that responding to misinformation would only "feed the beast," she now believes that "this is the ecosystem where we live and we need to deal with it."

## RETURNING TO HISTORY

Giselle Corbie, MD, began her presentation on the history of inequities faced by BIPOC communities by saying that the pandemic had lifted a veil on centuries of inequity and oppression, and that community members' willingness to believe misinformation was grounded both in this historical context and in present-day inequalities.

Dr. Corbie described how marginalized communities have faced systemic barriers to accessing quality health care, and have experienced discrimination, bias, and unequal treatment that ranged from being subjected to unethical medical experiments such as the USPHS Syphilis Study at Tuskegee University ("USPHS Study") to being forced to confront a wide variety of barriers to accessing care.

She described various aspects of the history of discriminatory and unethical behavior that have created mistrust, including:

- enslavement and the Jim Crow era;
- forced sterilization targeting Blacks, Native Americans and Puerto Ricans that were founded on a theory of eugenics that was widely accepted in the medical community at the time;
- removing Indian children from their families and placing them in boarding schools;
- police brutality and the carceral system;
- ongoing media misrepresentation of BIPOC communities; and,
- exclusionary immigration policies (e.g., Chinese Exclusion Act) and discriminatory treatment of immigrants (e.g., the internment of Japanese-Americans during World War II).

"This is not just about Black folk mistrusting," Dr. Corbie said. "This is systemic, consistent and ongoing. This historical context of inequalities fuels mistrust and skepticism among underserved communities and produces poorer outcomes in some populations than in others." Dr. Corbie said the spread of false information and stereotypes creates doubts among patients from BIPOC communities that can lead them to delay seeking care, helping to create the disproportionate impact of public health crises.

She had recommendations for how health care institutions could demonstrate trustworthiness, which included:

- Acknowledge historical and systemic issues: Be clear about the history of segregation, unjust practices and systemic biases that have contributed to mistrust, and account for past wrongdoings.



Giselle Corbie, MD

- Address health care disparities and make health equity a key component of strategic plans, including budgeting to improve access to quality care.
- Monitor and address conscious and unconscious bias.
- Build trust through transparency, both about the risks and benefits of care decisions and financial relationships with pharmaceutical interests and other stakeholders.
- Increase diversity in leadership.
- Strengthen communication, including active listening, using ‘plain language’ materials, and providing effective translation services.

Addressing the impact of misinformation, Dr. Corbie said, requires collaboration among systems, clinicians, patients, and communities. It also requires continued efforts to address disparities affecting marginalized communities.

Moderator Reggie Tucker-Seeley, SCD, vice president, health equity at ZERO-The End of Prostate Cancer, asked Dr. Corbie about COVID-19 vaccination and the Black community. Dr. Corbie said there was a lot of discussion about the community’s hesitance to be vaccinated, including allegations of conspiracy thinking. But this critique ignored serious issues that influenced vaccine uptake, such as how vaccines were allocated among regions and how patients needed to sign up for the vaccine online, marginalizing those without a computer or broadband access.

Dr. Corbie said that she had nearly completed her residency before learning about the USPHS study; she discovered it when a professor used only pictures of Black men to illustrate a lesson about syphilis. “Now people are tired of hearing about it,” she said. “But people are still living this—it is in the present-day consciousness whether we want to talk about it or not.”

## A REPORT FROM THE FRONT



Joe Smyser, PhD

Joe Smyser, PhD, the CEO of the Public Good Projects (PGP), said that he sits every day in front of dashboards based on all public media data: social media posts, traditional media, online videos, blogs and websites. He reported that the level of misinformation has gotten increasingly worse since 2019, despite various efforts to address it. “Not only is there more mis- and disinformation than ever before, but there is massive distrust and disillusionment with health care,” he said. “The politicization of misinformation has fueled the fire.” He noted that a significant majority of the world’s false information about vaccines is generated in the US, and that it takes only 24 hours for such claims to reach the world’s remotest corners. He predicted that the situation will continue to worsen, especially with the forthcoming presidential election campaign.

He said that information that is “local and personal” works best to address misinformation; indeed, he said that system leaders have told him that they can no longer direct patients to any federal resource because of the level of distrust in their communities. However, he said our ability to make use of this insight about the value of local efforts is undermined by the diminished states of local journalism and public health departments. “We see a massive hunger for authenticity and honesty,” Smyser said, noting that he included one-on-one conversations with health care professionals under the “local and personal” umbrella. “Showing up with empathy and a willingness to listen will take you far.”

Smyser also discussed a new PGP monthly newsletter that the ABIM Foundation has funded to help clinicians navigate the world of misinformation—it will summarize misinformation trends and offer fact checks and additional resources that they can use to inform their conversations with patients.

Finally, Smyser praised organizations that were standing up for the ideas of truth and science. “A medical board saying we are going to take the radical viewpoint of affirming that there is truth puts [the medical board] in the crosshairs,” he said. “We are living through a fundamental change in how society works. If you feel like nothing’s normal, that’s because it isn’t. And the cost of doing nothing is enormously high.”

## DEVELOPING PRACTICES TO BUILD TRUST

Forum participants then worked in small groups to develop concepts for how we could build trust with one of two groups: (1) individuals who are motivated by “medical freedom” ideologies and are deeply suspicious of scientific guidance or (2) members of BIPOC communities. Participants then could review other groups’ concepts and vote for ones they found particularly promising. These included:

- “Choosing Trust”: This concept would seek to increase Black patients’ trust through the systematic change of longstanding racist algorithms, starting by using glomerular filtration rate (GFR) and pulmonary function tests (PFT) that are uncorrected for race, accompanied by acknowledgment and apology.
- Truth and Reconciliation concepts: A number of groups worked on related ideas for demonstrating systems’ accountability to communities; these ideas shared a core of establishing a long-term restorative process to assist those who had been harmed in the past.
- A “Trust in Marginalized Communities” effort that would include serious penalties for hospitals that do not provide a specific minimum value of community benefits.
- Eliminating medical bankruptcy as part of effort to remove financial barriers that get in the way of building trust.
- Making primary care more accessible and increasing the diversity of the primary care workforce; this concept included the idea of creating a “trust toolbox” that clinicians could use to become more trustworthy.

## NAM/WHO/CMSS CREDIBLE INFORMATION PROJECT

Antonia Villarruel, PhD, RN, the Margaret Bond Simon Dean of Nursing at the University of Pennsylvania, described how YouTube asked the National Academy of Medicine in 2021 to develop a paper on identifying credible sources of information. She said this first paper had a limited focus on government and non-profit institutions and included three guiding principles: credibility, transparency and accountability. A second paper, co-sponsored by the World Health Organization and the Council of Medical Specialty Societies (CMSS), looked at a broader group of content producers, including individuals and for-profit groups.

Helen Burstin, MD, the CEO of CMSS, said that the second paper called for the consideration of factors such as conflicts of interest and disclosure of funding sources. She also said that the committee recognized that a credible source may sometimes put out non-credible information. Kevin Johnson, MD, the David L. Cohen University Professor at the University of Pennsylvania, and Dr. Burstin both said they did not want to suppress citizen science and evidence-based voices that lacked a medical credential, particularly voices of importance to vulnerable communities.



(left to right) Kevin Johnson, MD, Helen Burstin, MD, and Antonia Villarruel, PhD, RN

## REFLECTIONS ON DAY TWO

Catherine Lucey, MD, the executive vice chancellor and provost at UCSF, and Michael Howell, MD, the chief clinical officer at Google, shared their thoughts about the Forum's second day.

Dr. Lucey said she wished the group had talked more about the intrinsic value of trust and the “devastation that our insurance and payment system has on the trust that patients have in us.” She called for rethinking the care delivery model, saying physicians are not in position to fix the system, and said she feared that AI would mess up the system further.



(left to right) Catherine Lucey, MD and Michael Howell, MD

Dr. Howell said that as someone who thinks a lot about misinformation as part of his job, he found it helpful to know that an engaged community was interested in working on it. He said he wished that the group had spoken more about health literacy as a tool and a target, and about the adversarial information environment.

Dr. Lucey said that she had come across the concept of “technical debt” while reading about AI. When someone makes an expedient decision that ‘good enough’ is sufficient, that choice to settle has reverberations down the line. She said the time for such tweaking at the edges had passed. “People say it’s too hard to fix disparities,” she said. “Well, cancer is as complicated. We have chosen what to focus on. We can decide at our own institutional levels that once we decide to take care of you, we take care of you.”

She also stressed the need to create psychological safety in an increasingly diverse clinical environment, and for “thinking more deeply about how we can be ordinary citizens with special expertise rather than knowledge elites.”

Dr. Howell noted that lessons from the technology industry could be usefully applied in the effort to build trust with patients. He said that Google’s priority is to try to answer the question that people are asking—following the precept that if you focus on user, all else will follow. “Google is a company built on math,” he said. “If we make a button and no one clicks on it, we don’t blame the people, we blame the button.”

## INTRODUCING DAY THREE

David Coleman, MD, introduced the day as one where the group could build on what it had learned during the first two “depressing and inspiring” sessions to improve systems of care. Alongside this focus on systems, he said he thought “we’ve all been reminded that on the individual level, the core elements of medical professionalism, skill, humility, and truthfulness are the bedrock of the clinical encounter.”

## IHI AND THE ABIM FOUNDATION: TESTING DRIVERS OF TRUST

Kedar Mate, MD, president and CEO of the Institute for Healthcare Improvement (IHI), noted that previous Forums had identified ways in which systems struggled with trust, and said the ABIM Foundation had given IHI a grant to study what high-trust institutions were doing right. He described how IHI used multiple data sources to identify these high performers and then interviewed their leaders. He said that after 60–70 interviews, the IHI team could identify commonalities, such as acknowledging and apologizing for past mistakes and building systems to continuously listen to the patient and provider communities. Now, in the second stage of the project, IHI is seeking to apply the framework it developed through the first phase to seven new institutions that volunteered to participate. Leaders of two of those seven – Parkland and Oak Street – were also on this panel.



(left to right) Ali Khan, MD, Kedar Mate, MD, Fred Cerise, MD, and Donald M. Berwick, MD

Ali Khan, MD, chief medical officer for value-based care strategy at Oak Street Health, described how Oak Street was using a for-profit model to deliver primary care in low-income areas in 75 markets, using teams that are largely composed of members of BIPOC communities and immigrants. He described the possibility of better understanding clinician trust by participating in the IHI project as “an opportunity to either validate or challenge our deeply-held assumptions.”

Fred Cerise, MD, described how community trust was essential to Parkland’s ability to effectively perform its role in protecting public health in Dallas County. He said Parkland wanted to learn more about how its community interactions were being received and whether it was focusing on the right things.

Dr. Cerise said Parkland initially focused on its community asthma program, which it saw as a bellwether for trust. As the project leaders learned more, it became increasingly apparent that the community health workers (CHWs) who staffed that program believed they weren’t being heard. Addressing that became Parkland’s focus, and the project team is identifying issues that make the CHWs feel like they are not part of the team. “Practically, it’s a process of acknowledging and apologizing,” Dr. Cerise said. “If we really are going to be improving the health of the community, we have to go in humble.”

Dr. Mate said that other participating systems had also shifted some of their focus to developing a deeper sense of trust within the care team. “Our prediction had been that these were relatively distinct paths,” he said. “But there seems to be an inter-relationship between the two.”

Dr. Khan said Oak Street focused on the Dallas-Fort Worth market because it featured a large discrepancy between employees’ belief in their manager and in their overall organization. “You could walk in to a clinic there and see that something was amiss culturally,” he said. He believed employees did not feel autonomy and, similar to Parkland, also felt unheard. He also said there was a real hunger for authentic leadership, alongside doubts that it will arrive.

Daniel Wolfson noted that the ABIM Foundation envisions that the next step for this effort would be the creation of a national campaign.

## WAYS TO BUILD PUBLIC TRUST

Participants again worked in small groups to formulate ideas to build public trust, and then voted for their favorite concepts, which included:

- **Reducing medical debt:** This group proposed an effort to reduce medical debt by 50 percent over a 5-year period. They suggested creating a “star rating system” that would grade hospitals on their debt collection practices, in an attempt to discourage the use of egregious methods.
- **Bi-directional health information exchange:** Under this idea, health systems would employ health information ambassadors who would work in their communities and report back on critical issues, including misinformation that is spreading in the community. The creators of the idea believed it would help create longitudinal, permanent relationships between systems and communities.
- **Improve primary care:** Create longitudinal cost-free relationships between clinicians and patients by, among other things, expanding the workforce, increasing payment for primary care visits, and relying on e-consults

- **Access to care within a week:** Adopt a series of steps (e.g., incentives or even requirements for medical graduates to provide primary care, expand use of international medical graduates, expand use of e-consults) to assure that all patients can see a clinician within seven days
- **Accelerate spread of IHI Model:** This would be an effort to spread IHI's learnings about building authentic community relationships across the health care system, to foster stronger ties and build trust between systems and communities.

## ADVICE FOR THE ABIM FOUNDATION

A panel of Forum participants provided their thoughts for how the ABIM Foundation could best advance public trust. Harkening back to Mr. Smyser's insight that the most effective information is local and personal, Debra Ness, MS, past president of the National Partnership for Women & Families, recommended focusing on best practices for building transparent and genuine community partnerships between health systems/providers and local leaders/community members. She said her second choice would be to get involved with the medical debt issue. More generally, she talked about the Foundation's skill in partnering and called for ABIMF to rely on co-creation in developing future activities.



(left to right) Monica Lypson, MD, Neel Shah, MD, Richard Baron, MD, Andy Bindman, MD, and Debra Ness, MS

Monica Lypson, MD, vice dean for education at Columbia University Vagelos College of Physicians & Surgeons, called for focusing on changing our paradigm of education so that students are learning from the community and thinking differently about how we approach problems. She called for educators in the health care professions to think about what they need to learn from those most marginalized, either patients or learners, to improve their teaching, especially in regards to misinformation. She also suggested the limits of the Forum audience, arguing that no Forum participant was likely struggling with medical debt as one example.

Andy Bindman, MD, the EVP and chief medical officer at Kaiser Permanente, called for going beyond seeking to create alliances with community organizations to investing in them so that they can be more effective and stable partners. Ms. Ness pointed to the potential of thinking about your workforce as part of your community and learning from it.

Dr. Bindman also said he was struck by the importance of developing strategies for reinvesting in primary care, which is a source of conversations to build public trust. Ms. Ness stressed the need to address the divide between primary care physicians and specialists.

Neel Shah, MD, chief medical officer at Maven Clinic, asked how we can have a trustworthy system when one in three people have medical debt, but pointed to the primacy of the issue of information and who owns it. He referred to the clinician in the trenches, trying to be responsive to the funnel of information that patients are consuming, and noted that most patients come to clinicians for information but also want respect for the information they bring to the visit. He also reflected on a lesson he drew from author and activist Sarah Schulman's *Let The Record Show*, a book about ACT UP New York and the AIDS crisis in the 1980s and 1990s. He said the core concept he drew from the book was that "progress doesn't require consensus; it requires a simultaneity of response." He said he thought that was a beautiful way of thinking about how participants might move forward in their various capacities to address the problems discussed throughout the Forum.

Dr. Baron thanked the panelists for their advice, agreeing with the theme that the Foundation should not go anywhere by itself, and that its actions should be informed by those with a variety of views. He also talked about the importance of building humility into our work.

## FINAL REFLECTIONS

Professors Grossman and Rosenfeld re-joined Dr. Baron for a final discussion. Professor Grossman emphasized that a significant part of skepticism and distrust in health care is tied to religion and religious communities, and stressed the importance of keeping in mind those people whose world views and communities are shaped by religion as the



(left to right) Lewis Grossman, JD, and Sophia Rosenfeld, PhD

profession considers how to address misinformation and build trust. Professor Grossman also said that most people do not prioritize risk minimization and health maximization above all other potential benefits, and that it would serve the medical establishment well to consider the other values, secular and religious, that people bring into the equation.

Professor Rosenfeld talked about how the meeting had treated BIPOC communities and libertarian ones as very distinct, but that the two groups share a sense of being excluded and it could be interesting to consider whether there might be commonalities in the profession's approach to them. She said she came to the meeting wondering whether issues of democracy and truth were simply far

afield from health care. But she said she repeatedly heard people talk about how the public wants to be heard and seen, sensory metaphors that are central to democratic theory.

Professor Grossman encouraged the group to realize that mistrust in the medical establishment is tied to historical forces. “By all means try to overcome and build bridges, but you are part of a much broader sweep of distrust that is threatening many parts of our civilization all at once,” he said.

Dr. Baron asked about their impressions of the meeting. Professor Rosenfeld noted that she heard what she thought of as an unusual mix of both utopian goals (e.g., adopting a single payer system in the US) and pragmatic, smaller-scale goals from the group. She said she thought it was important to have large goals that may not be achieved in your lifetime, alongside more modest ones with different time frames. Professor Grossman said he was encouraged that participants were thinking at a broad policy level, but cautioned that increasing the economic fairness of the system will not be enough to restore trust in the medical profession; reformers must also address culture and tradition.

Dr. Baron closed the meeting by noting that physicians are not only members of the “knowledge elite” but are people, too, and they—and the system as a whole—needs to be better at “recognizing the ‘peopleness’ of others.”



Richard Baron, MD

## TWO SPECIAL SESSIONS WERE HELD ON THE SECOND DAY OF THE FORUM:

### Artificial Intelligence

Panelists (Abha Agrawal, MD, chief medical officer at Humboldt Park Health, Vineet Arora, Michael Howell and Kevin Johnson) discussed the promise and challenges of AI. Potential benefits included improving diagnoses, predicting outcomes, relieving documentation burdens, and enhancing simulation. The panelists were concerned about privacy issues, over-dependence on and inaccuracies in AI, and embedded biases. Everyone agreed that we were about to see dramatic leaps in the capabilities of AI, and one panelist recommended that anyone who had not yet explored Chat GPT do so before the technology reaches such an advanced stage that they feel left behind.

### Medical Debt

Panelists Noam Levey, senior correspondent at KFF Health News, and Don Berwick, MD, president emeritus and senior fellow at the Institute for Healthcare Improvement, discussed the staggering consequences of medical debt in the US, where 100 million people carry some form of health care debt. They also noted that those with such debt are less likely to trust their clinicians (38 percent of those with debt lack trust compared to 27 percent of those who do not.) Session participants then proposed their own solutions to the medical debt crisis, which became part of the discussion during the Forum's third day.

## CELEBRATING TWO DECADES OF LEADERSHIP: DANIEL WOLFSON



This Forum was the final one organized by Daniel Wolfson, who served as Executive Vice President and Chief Operating Officer of the ABIM Foundation from 2002–2023. Daniel's contributions to ABIM, the ABIM Foundation and the health care system as a whole were recognized throughout the Forum, highlighted by a reception in his honor. Participants had the opportunity to suggest words that they associated with Daniel, with the most popular choices including generous, creative, lovable, kind and loyal. Some who worked with Daniel over the years spoke about their deep affection and appreciation for him. Don Berwick's words represented the feelings of the group: "As much as I admire what you've done, I admire even more who you are."

