



# 2020 SIGNATURE SERIES: SUMMIT

## VOICE OF THE PATIENT

# **“ARE THEY TRUSTWORTHY?” – THE PARADOX OF THE INFORMED PATIENT**

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Recorded: October 16, 2020

“Are they (providers and healthcare organizations)  
trustworthy?”:  
The paradox of the informed patient

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Summit: Voice of the Patient  
Keynote Address  
Alliance for Health Policy  
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William C. “Bill” Jenkins, PhD, MPH – Pioneering epidemiologist, educator, and one of the leaders within the US Public Health Service responsible for ending the Tuskegee Study of Untreated Syphilis in the Negro Male (died February 17, 2019)







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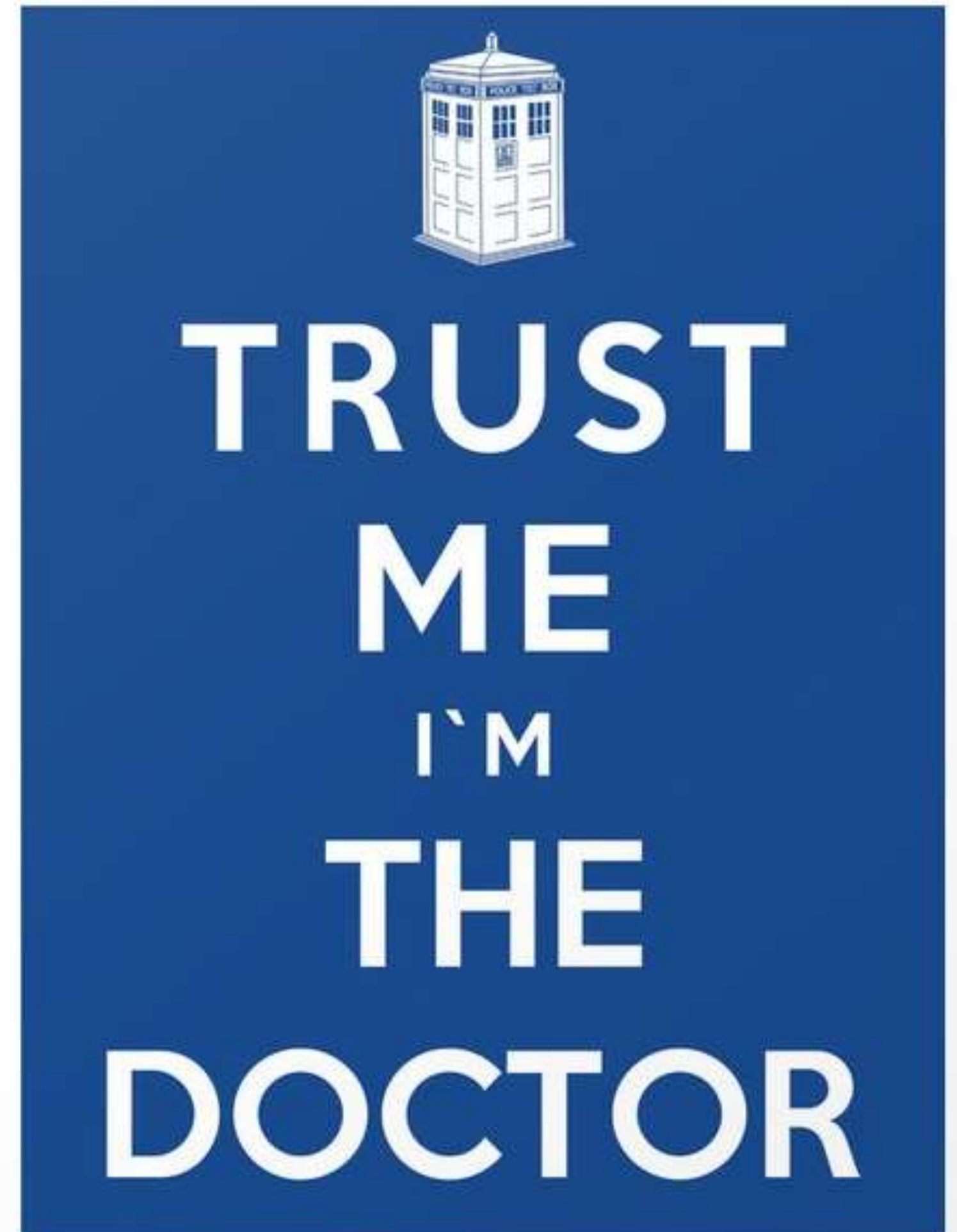
# Center for Research on Men's Health

“On a team, it’s not the strength of in the individual players, but the it is the strength of the unit and how they all function together.” – Bill Belichick



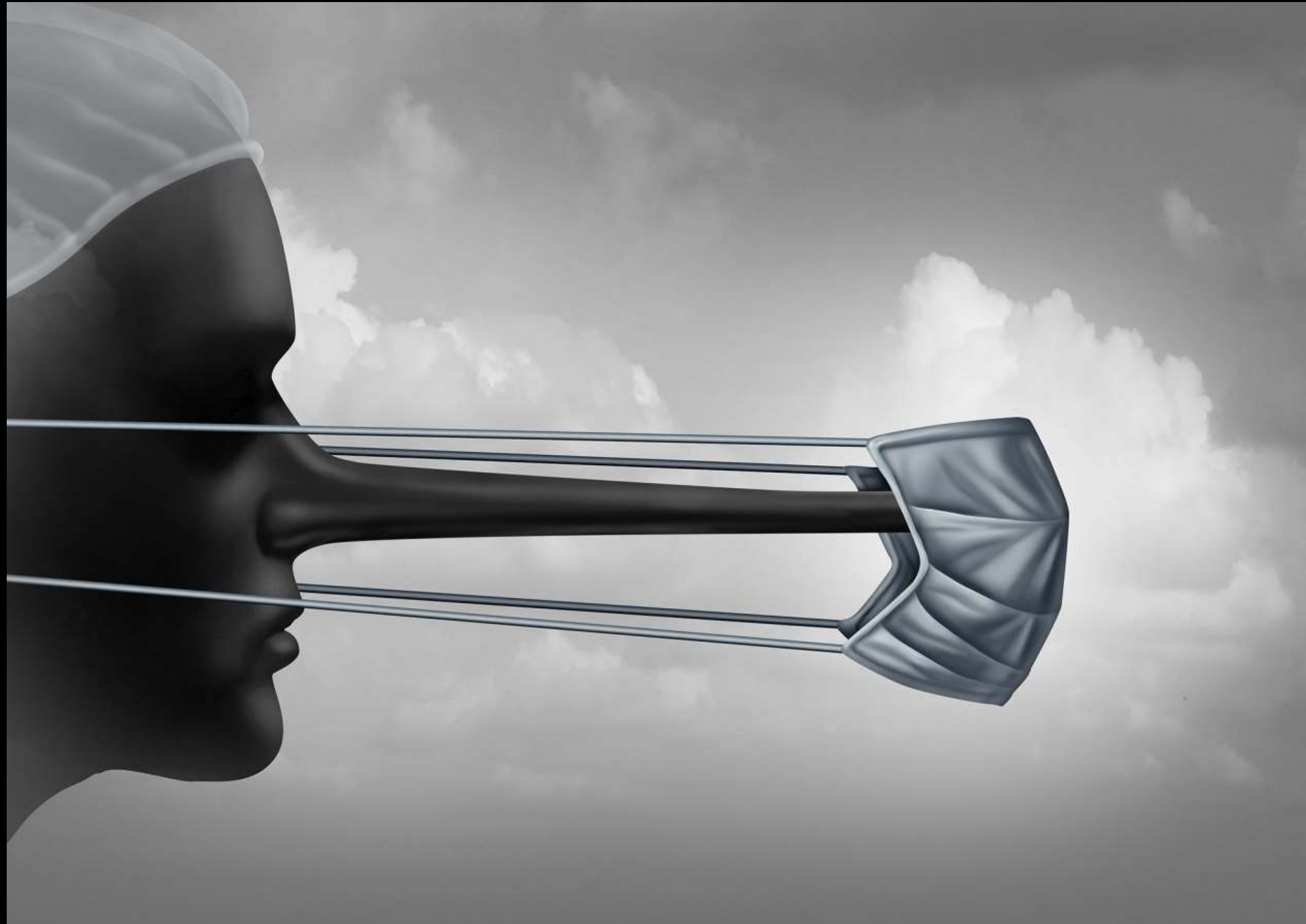
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- Patients need providers and healthcare institutions
- Patients need to be well-informed
- What should patients do when they learn that all providers and healthcare institutions are not trustworthy?





Lack of trust is often framed as something to change among patients rather than highlighting the need for providers and healthcare institutions to demonstrate that they are trustworthy.



<https://www.chicagobusiness.com/forum-ideas-health-care/we-must-stop-fanning-flames-medical-mistrust>

# KEY POINTS

- Define trust and other key terms
- Explore the legitimate reasons patients may not trust healthcare providers
- Focus on helping providers and organizations become more trustworthy rather than blaming patients for lack of trust

# Trust

“...trust is belief in a person’s competence to complete a certain task.”

(Griffith, et al, in press)



TRUST

**Takes years to build,  
seconds to break and  
forever to repair.**



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# EFFECTIVE PATIENT CARE IS BASED ON RELATIONSHIPS AND TRUST

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### THE CARE OF THE PATIENT\*

FRANCIS W. PEABODY, M.D.

BOSTON

It is probably fortunate that systems of education are constantly under the fire of general criticism, for if education were left solely in the hands of teachers the chances are good that it would soon deteriorate. Medical education, however, is less likely to suffer from such stagnation, for whenever the lay public stops criticizing the type of modern doctor, the medical profession itself may be counted on to stir up the stagnant pool and cleanse it of its sedimentary deposit. The most common criticism made at present by older practitioners is that young graduates have been taught a great deal about the mechanism of disease, but very little about the practice of medicine—or, to put it more bluntly, they are too “scientific” and do not know how to take care of patients.

science to the diagnosis and treatment of disease is only one limited aspect of medical practice. The practice of medicine in its broadest sense includes the whole relationship of the physician with his patient. It is an art, based to an increasing extent on the medical sciences, but comprising much that still remains outside the realm of any science. The art of medicine and the science of medicine are not antagonistic but supplementary to each other. There is no more contradiction between the science of medicine and the art of medicine than between the science of aeronautics and the art of flying. Good practice presupposes an understanding of the sciences which contribute to the structure of modern medicine, but it is obvious that sound professional training should include a much broader equipment.

The problem that I wish to consider, therefore, is whether this larger view of the profession cannot be approached even under the conditions imposed by the present curriculum of the medical school. Can the practitioner's art be grafted on the main trunk of the funda-



# Trust in the health care professional and health outcome: A meta-analysis

Johanna Birkhäuser<sup>1\*</sup>, Jens Gaab<sup>1</sup>, Joe Kossowsky<sup>1,2,3</sup>, Sebastian Hasler<sup>1</sup>, Peter Krummenacher<sup>4</sup>, Christoph Werner<sup>1</sup>, Heike Gerger<sup>1</sup>

**Citation:** Birkhäuser J, Gaab J, Kossowsky J, Hasler S, Krummenacher P, Werner C, et al. (2017) Trust in the health care professional and health outcome: A meta-analysis. PLoS ONE 12(2): e0170988. doi:10.1371/journal.pone.0170988

## Objective

To examine whether patients' trust in the health care professional is associated with health outcomes.

## Study selection

We searched 4 major electronic databases for studies that reported quantitative data on the association between trust in the health care professional and health outcome. We screened the full-texts of 400 publications and included 47 studies in our meta-analysis.

## Conclusions

From a clinical perspective, patients reported more beneficial health behaviours, less symptoms and higher quality of life and to be more satisfied with treatment when they had higher trust in their health care professional. There was evidence for upward bias in the summarized results. Prospective studies are required to deepen our understanding of the complex interplay between trust and health outcomes.

“...we should only trust the truly trustworthy,”  
because when trust is violated or diminished,  
the reaction is often not simply one of  
disappointment but a sense of betrayal.

(Fritz & Holton, 2019; Griffith, et al., in press)



# Trust Family more than Doctors

“You know, a doctor come and tell you something.... But... these people [family] been taking care of me.... So, I think on some unconscious level, that we tend to still stick with the people who we trust and the people who we’re closest to and what they’re telling and teaching us.”

(Griffith, et al., 2010)



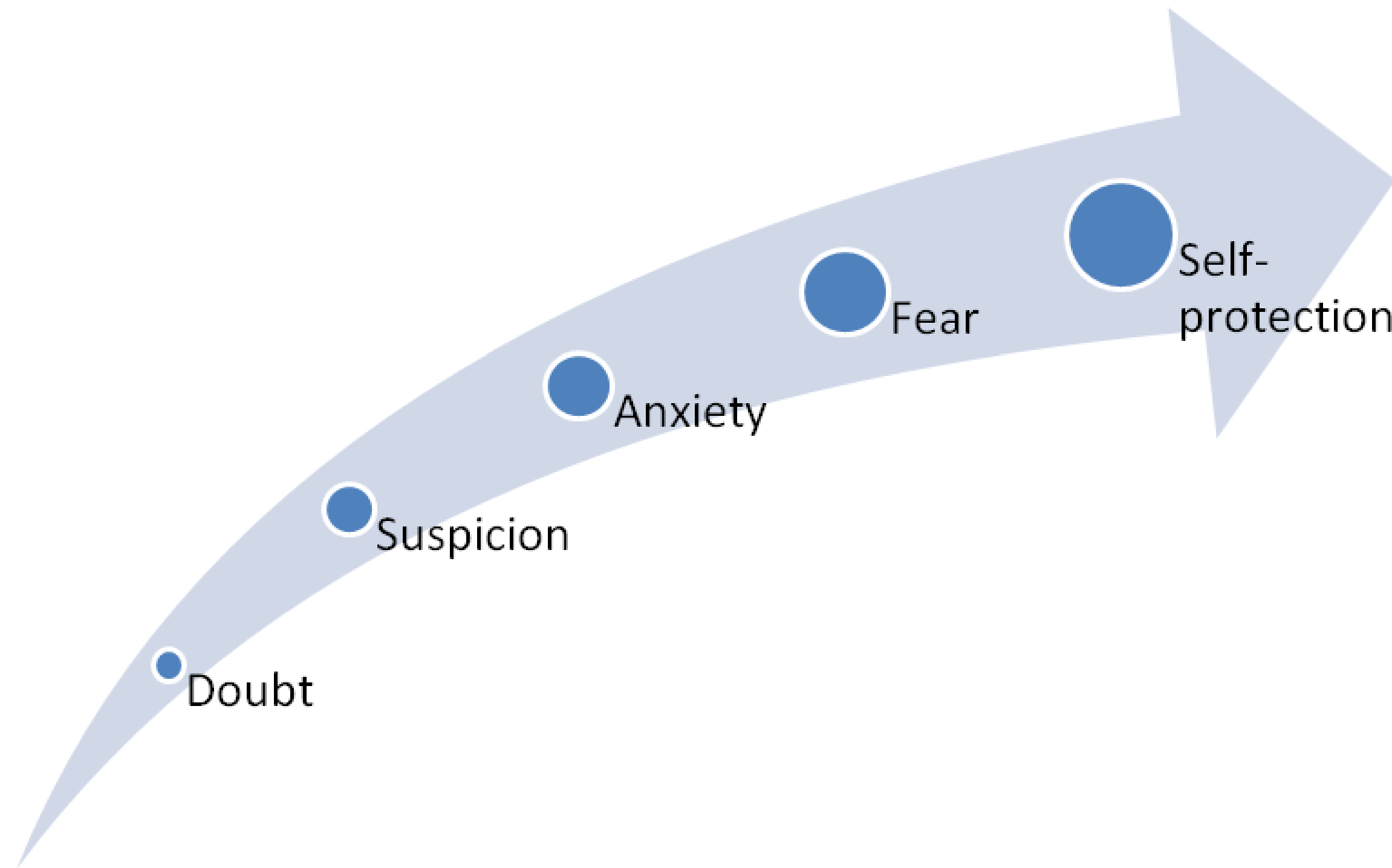
# Distrust

“...**distrust** is the idea that the patient actively questions and doubts the motives, sincerity, genuineness, and trustworthiness of the specific provider, researcher, organization, or institution.”

**Note:** with distrust there is a specific direct object

(Griffith, et al, in press)

# Stages of Distrust



<https://leadingwithtrust.com/2014/05/18/5-stages-of-distrust-and-how-it-destroys-your-relationships/>

# Mistrust

“Mistrust also is often a **general sense of unease or suspicion...** that is predicated either on the notion that the provider or healthcare entity may not act in the patient’s best interest and they may in fact actively work against the patient. **Mistrust may originate from distinct historical experiences linked to group identity, personal experience, vicarious experiences, and oral histories.**”

**Note:** with mistrust there is NOT a specific direct object

(Griffith, et al, in press)





# Tuskegee U.S. Public Health Service Study of Untreated Syphilis in the Negro Male: 1931-1972



<https://historycollection.com/20-photos-tuskegee-syphilis-study/2/>



The purpose of the study was to observe the natural progress of untreated syphilis in rural African-American men. The patients were told that they were receiving free health care from the United States Government. *They were not.*





# The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?

Dwayne T. Brandon, PhD; Lydia A. Isaac, MS; and Thomas A. LaVeist, PhD

**Objectives:** To examine race differences in knowledge of the Tuskegee study and the relationship between knowledge of the Tuskegee study and medical system mistrust.

**Methods:** We conducted a telephone survey of 277 African-American and 101 white adults 18–93 years of age in Baltimore, MD. Participants responded to questions regarding mistrust of medical care, including a series of questions regarding the Tuskegee Study of Untreated Syphilis in the Negro Male (Tuskegee study).

**Results:** Findings show no differences by race in knowledge of or about the Tuskegee study and that knowledge of the study was not a predictor of trust of medical care. However, we find significant race differences in medical care mistrust.

**Conclusions:** Our results cast doubt on the proposition that the widely documented race difference in mistrust of medical care results from the Tuskegee study. Rather, race differences in mistrust likely stem from broader historical and personal experiences.



# Trustworthiness of medical research?

“These participants’ perspectives highlight how the history of these unethical research studies that are often discussed as abstract historical events in a bygone era are actually quite present and relevant to the lives and experiences of many African Americans...”

(Griffith, et al., 2020)



# Trustworthiness of medical research?

“Because medical providers often are the ones who also are conducting research and medical research may take place in the same settings as people receive care, it is important to realize how negative experiences with care can adversely affect trust in research and researchers.”

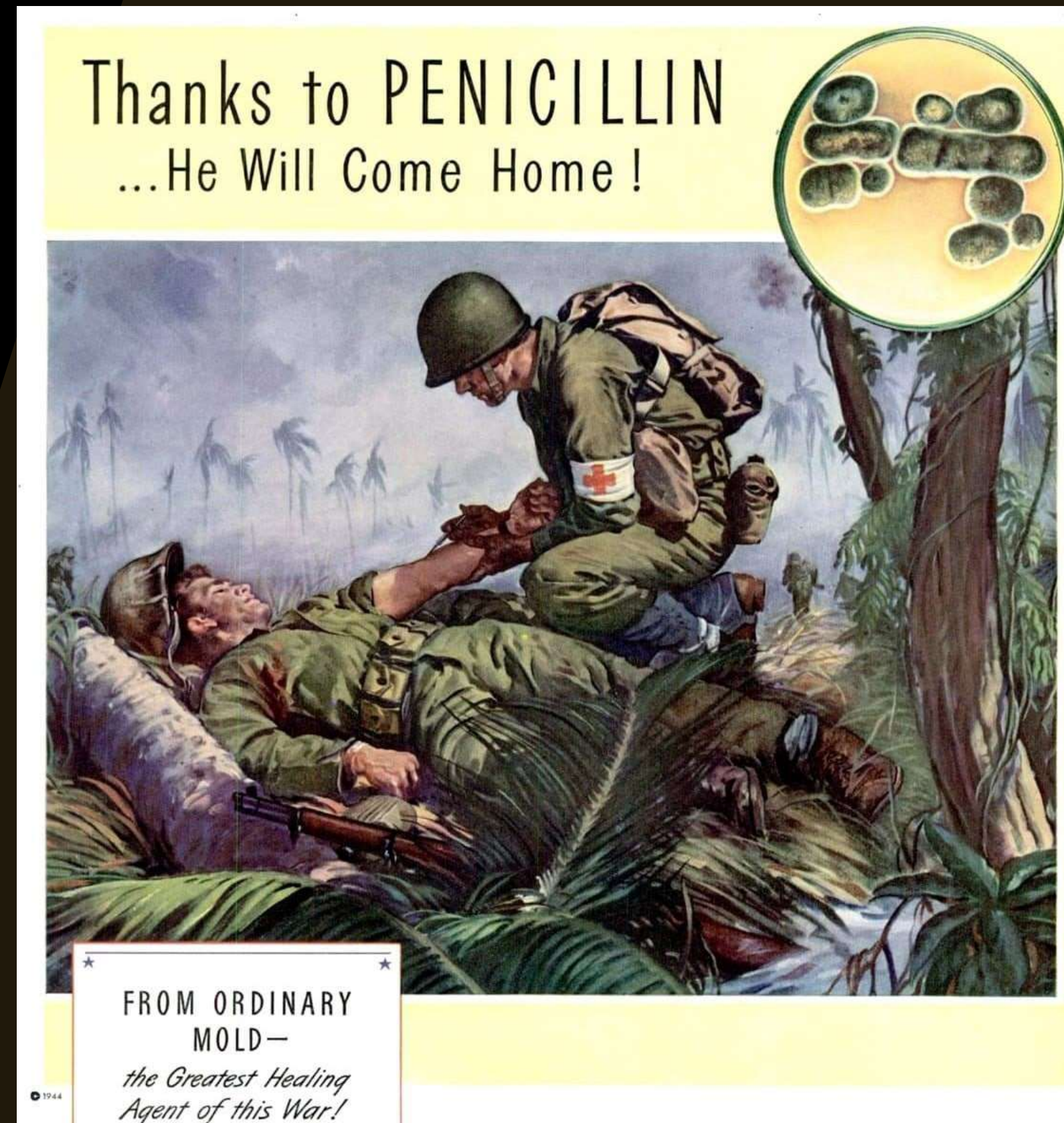
(Griffith, et al., 2020)

# Trustworthiness of medical research?

As one focus group participant explained, “Corporations and different things who can have other interests aside from just finding cures and finding ways to improve health. They have interest in what money's getting made, what they already have developed that they're selling...it kind of hurts the process a little bit... the conversation changes and it isn't always just in the same best interest of public health.”

(Griffith, et al., 2020)

# The first American patient was treated with penicillin on March 14, 1942





The USPHS collaborated with local physicians to restrict surviving patients from treatment, as it would contaminate the study data.



<https://historycollection.com/20-photos-tuskegee-syphilis-study/2/>



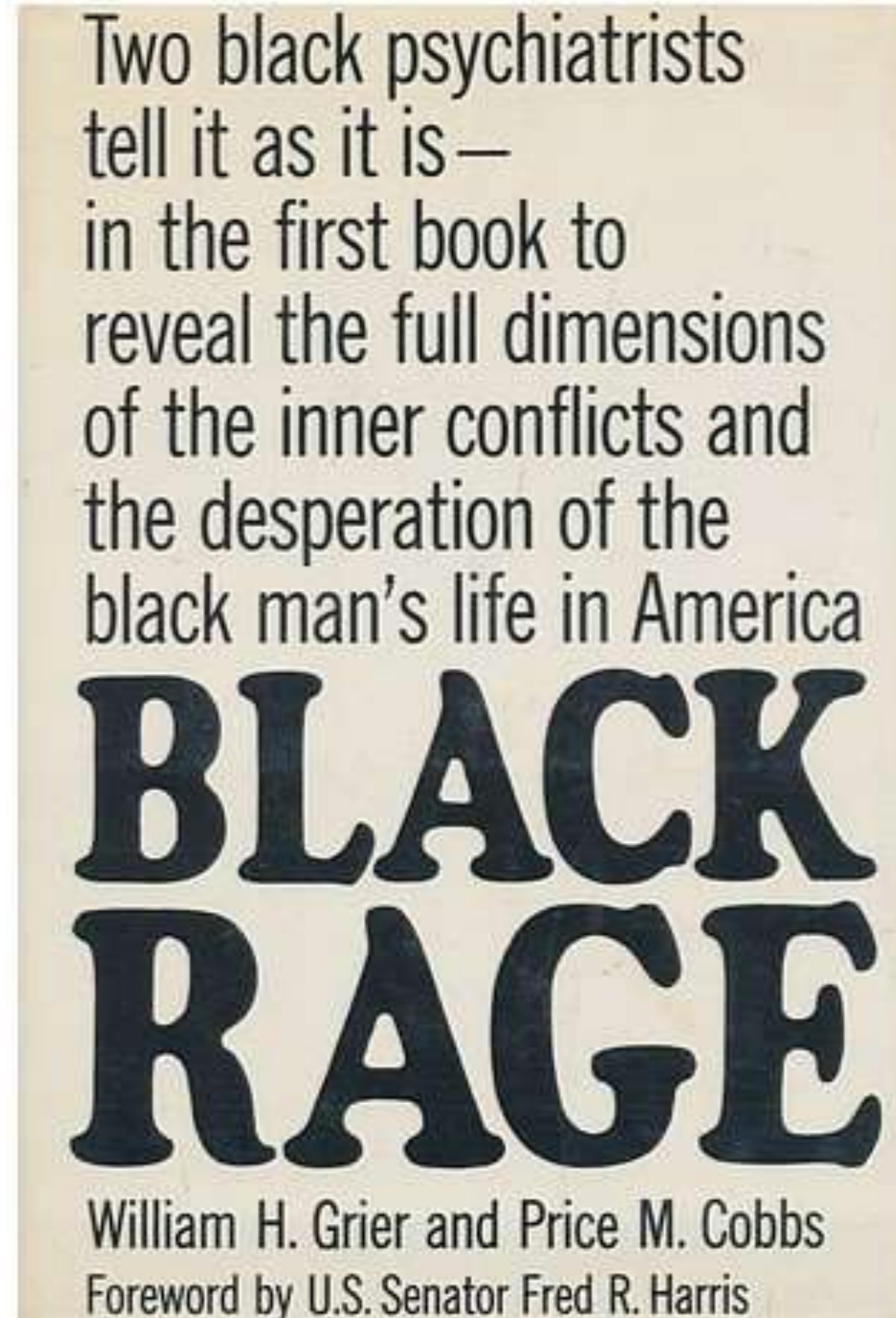
“Those who initially started the trial actually had reputations as committed public health physicians with commitment and concern regarding the health of Negroes.”

Brawley, 1998; Jenkins, et al., 2003



<https://historycollection.com/20-photos-tuskegee-syphilis-study/2/>

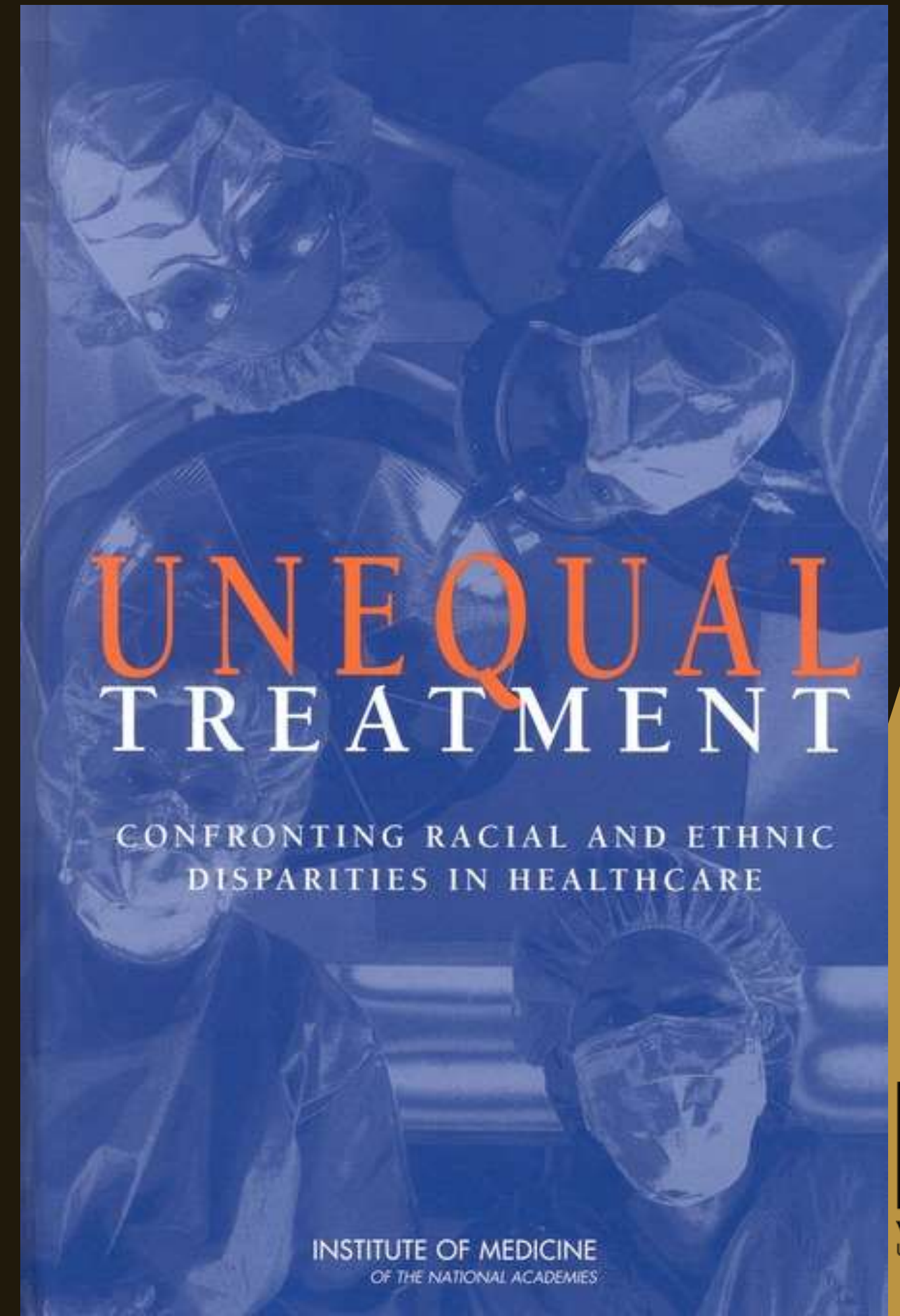
More than 50 years ago, Grier and Cobbs (1968) argued that African Americans' suspicions and fears that many sectors of American society are not trustworthy were **logical and accurate interpretations** of their perceptions and experiences.





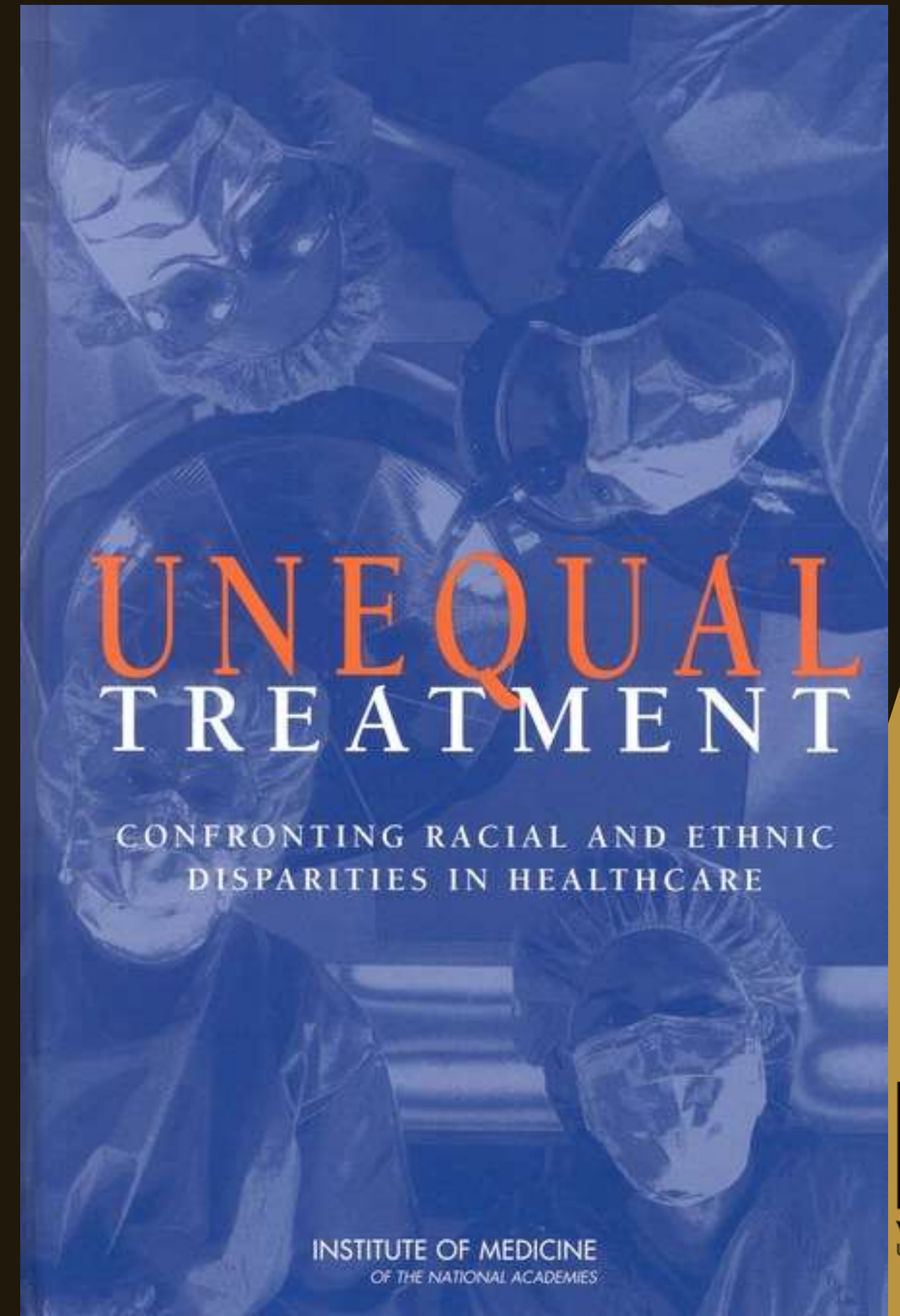
# Healthcare Disparities

“...racial or ethnic differences in the quality of healthcare that are not due to access- related factors or clinical needs, preferences, and appropriateness of intervention”



# Healthcare Disparities

Dr. Alan Nelson, Chair of the Chair of the Unequal Treatment Study Committee said, “I think most physicians have the same response I did. My first impulse was to say ‘This couldn’t be. How could well-meaning, well-educated physicians and other clinicians, who devote their life to helping people, provide care that results in these disparities?’”





# Trustworthiness vs. Trust

“For groups with a history of experiencing racism, discrimination or exclusion, even those that are not defined by race and ethnicity, concerns about the trustworthiness of health professionals, medical care, health research and institutions that deliver health services abound.”

(Griffith, 2020)

# Towards a More Inclusive and Dynamic Understanding of Medical Mistrust Informed by Science

Jessica Jaiswal<sup>a,b,c</sup> and Perry N. Halkitis<sup>b,d,e,f,g</sup>

BEHAVIORAL MEDICINE

2019, VOL. 45, NO. 2, 79–85

<https://doi.org/10.1080/08964289.2019.1619511>

“While mistrust is often referred to as a phenomenon existing within an individual or community, we must **rethink this conceptualization** and **instead locate mistrust as a phenomenon created by and existing within a system that creates, sustains and reinforces racism, classism, homophobia and transphobia, and stigma.**”



# KEY POINTS

- Define trust and other key terms
- Explore the legitimate reasons patients may not trust healthcare providers
- Focus on helping providers and organizations become more trustworthy rather than blaming patients for lack of trust

*That's all Folks!*

