

# Trustworthiness

A Principle for Processes, Practices, and Partnerships to Improve Health among Disadvantaged and Disenfranchised Populations

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- I will NOT include discussion of investigational or off-label use of any medical product in this presentation.

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# Overview

- Era of Distrust and Mistrust
- Misadventures in Medical Practice and Research
- Repairing Breaches and Building Bridges

# Trust

- Belief in the reliability, truth, ability, or strength of someone or something



# Distrust

- Lack of trust or suspicion stemming from experience or certain knowledge.





# Era of Distrust and Mistrust



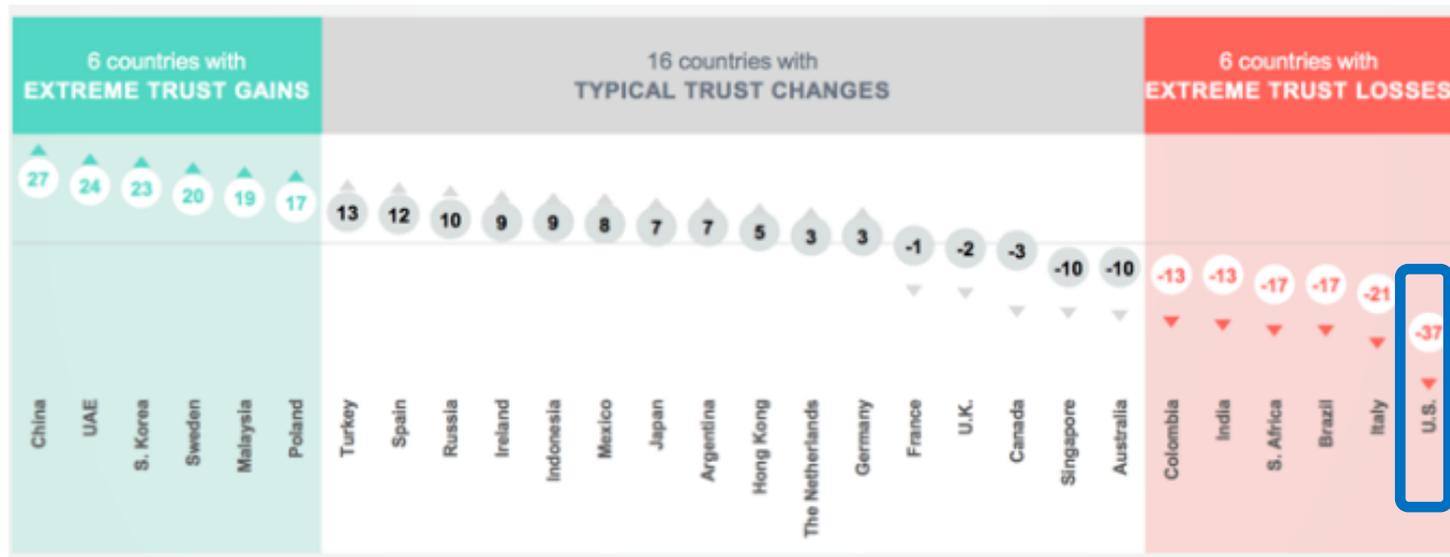
## GLOBAL

# Trust Is Collapsing in America

When truth itself feels uncertain, how can a democracy be sustained?

URI FRIEDMAN JANUARY 21, 2018

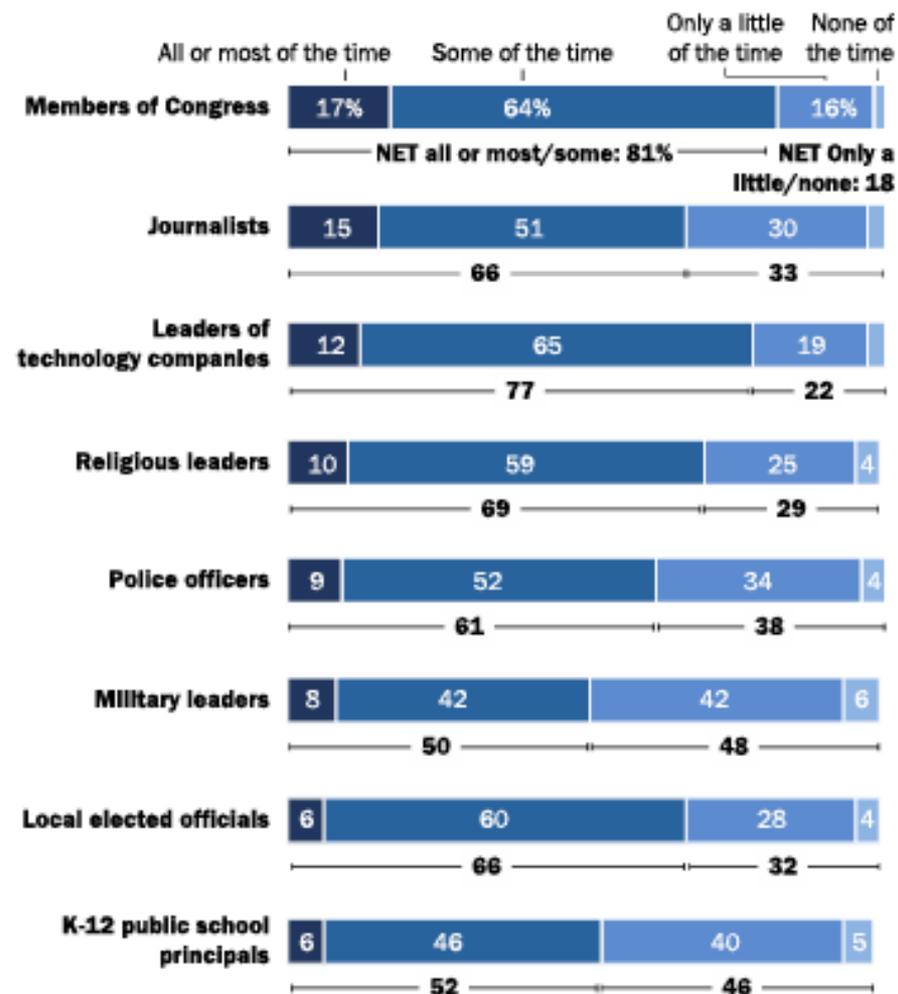
## Percent Change in Trust in Government, Media, Business, and NGOs, 2017 — 2018



2018 EDELMAN TRUST BAROMETER

## Most think key institutional actors behave unethically at least a little of the time

% of U.S. adults who think \_\_\_\_\_ act unethically



Note: Those who declined to answer are not shown.

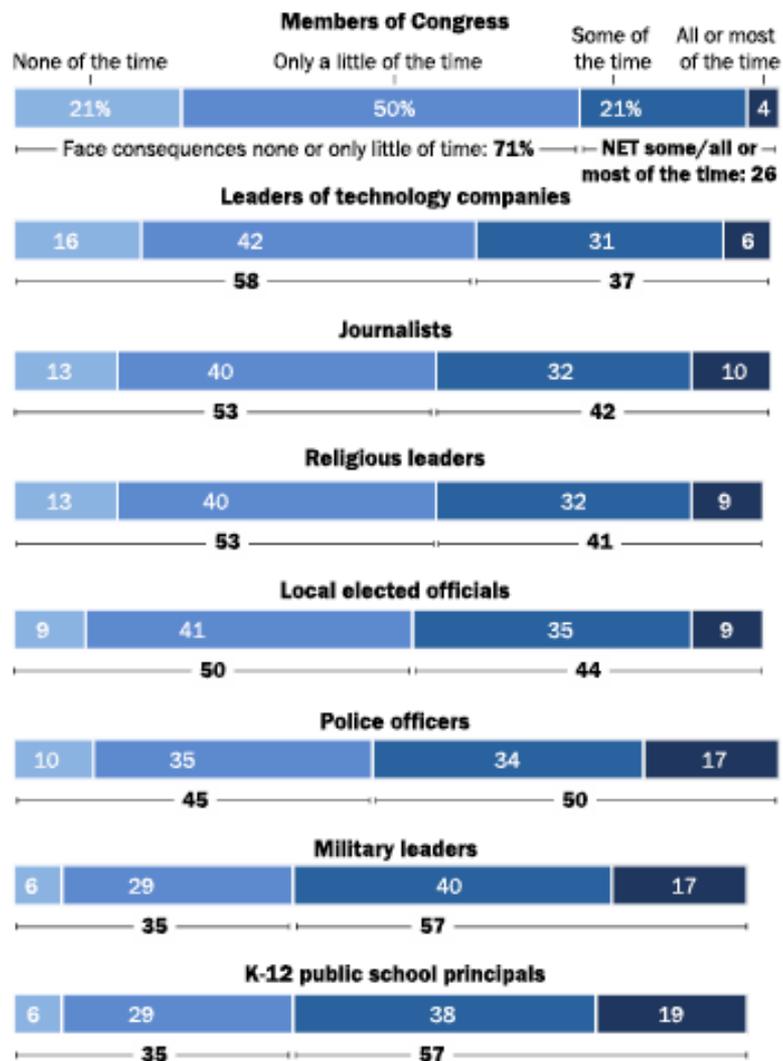
Source: Survey conducted Nov. 27-Dec. 10, 2018, among U.S. adults.

"Why Americans Don't Fully Trust Many Who Hold Positions of Power and Responsibility"

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## Americans generally don't think unethical behavior by those in positions of power and responsibility results in serious consequences

How often, if at all, do you think \_\_\_\_\_ face serious consequences when they act unethically?



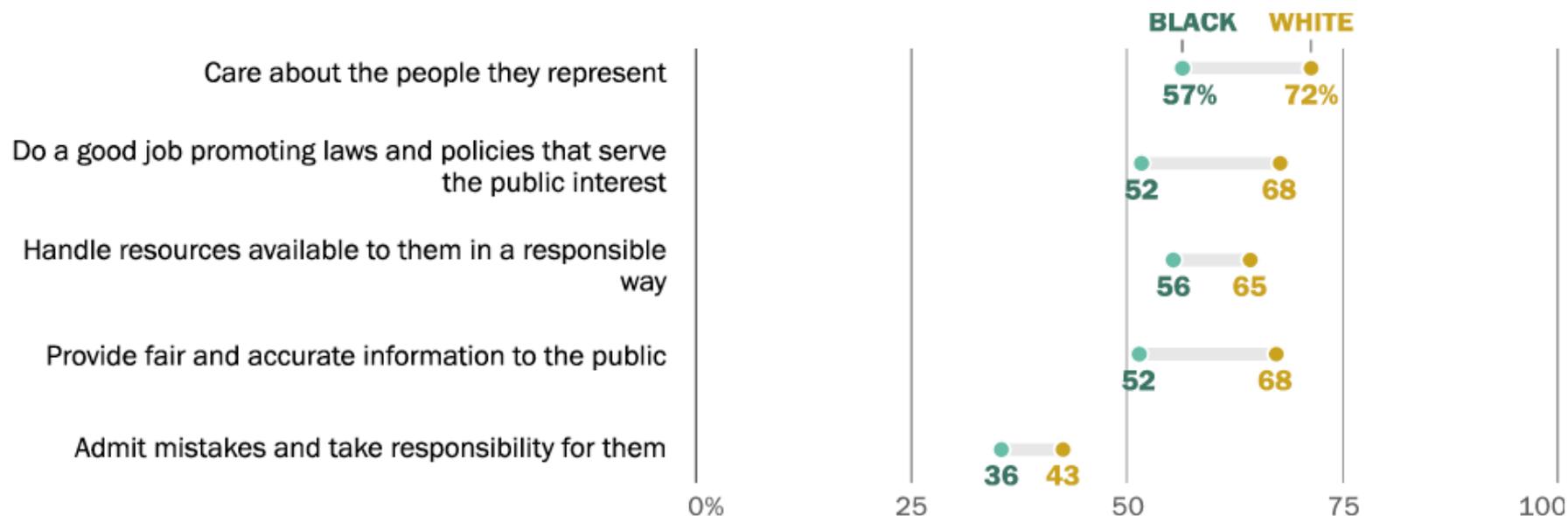
Note: Those who declined to answer are not shown.

Source: Survey conducted Nov. 27-Dec. 10, 2018, among U.S. adults.

"Why Americans Don't Fully Trust Many Who Hold Positions of Power and Responsibility"

## Black people are less confident in local officials doing their jobs well than white people

*% of U.S. adults who say local elected officials \_\_\_\_\_ all or most, or some of the time*



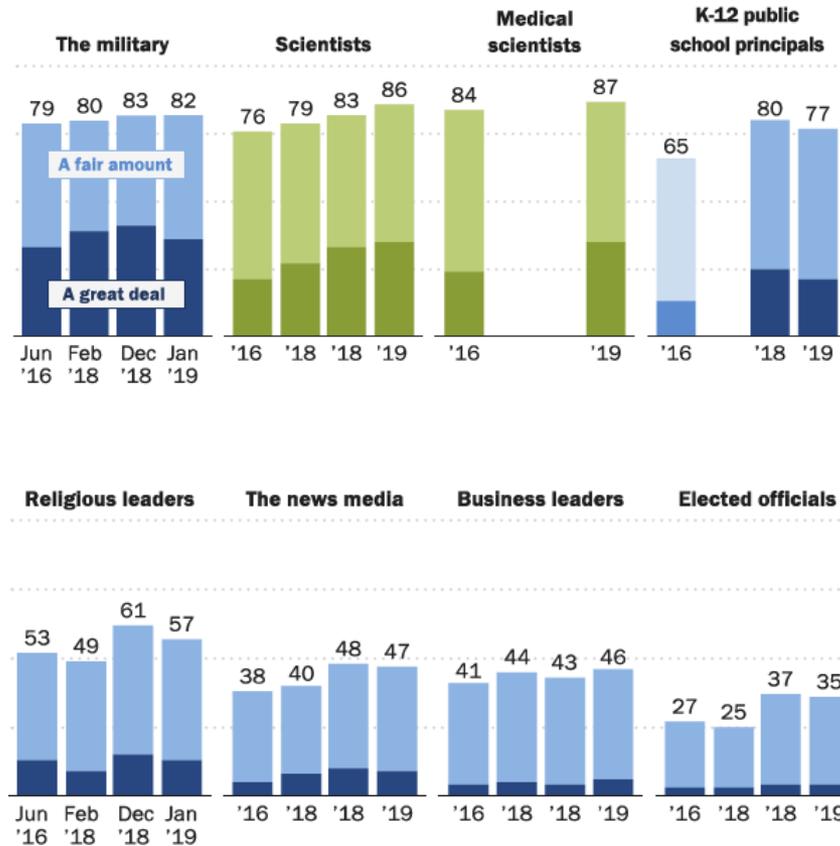
Source: Survey conducted Nov. 27-Dec. 10, 2018, among U.S. adults.

"Why Americans Don't Fully Trust Many Who Hold Positions of Power and Responsibility"

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# Americans' confidence that scientists act in the public interest is up since 2016

*% of U.S. adults who say they have a great deal or fair amount of confidence in each of the following groups to act in the best interests of the public*



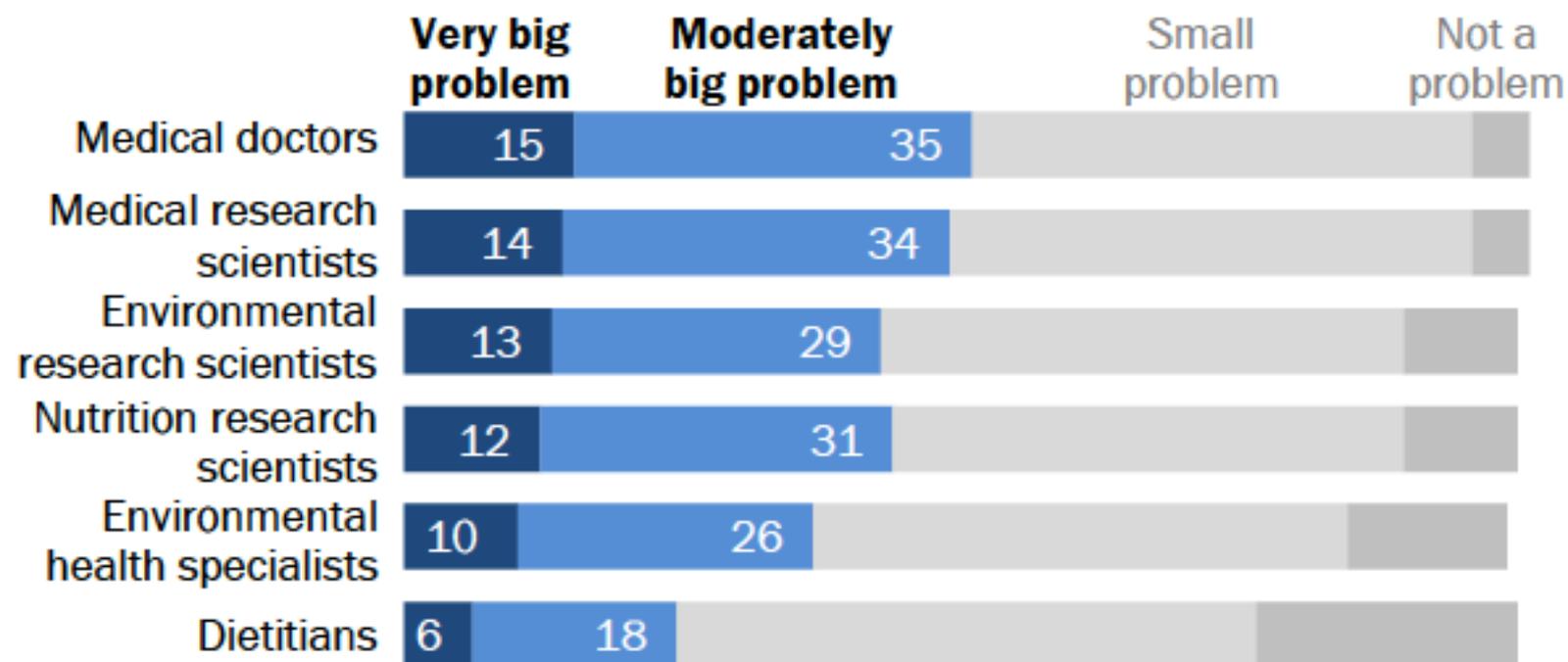
Source: Survey conducted Jan 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

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## The public is divided over whether misconduct by medical professionals is a big problem

*% of U.S. adults who say misconduct among each group is a ...*



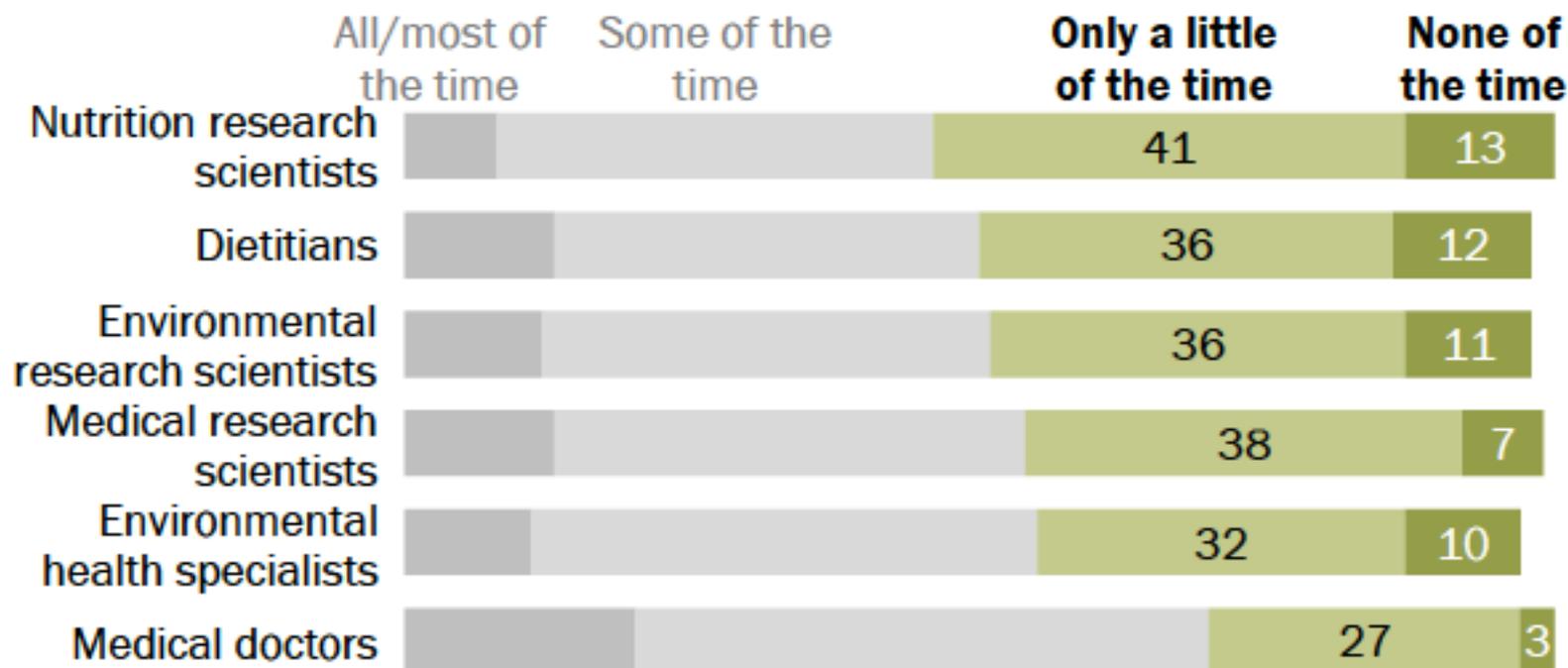
Note: Respondents who did not give an answer are not shown.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

## Many Americans are skeptical that scientists who engage in misconduct face serious consequences

*% of U.S. adults who say when misconduct occurs, each group faces serious consequences ...*



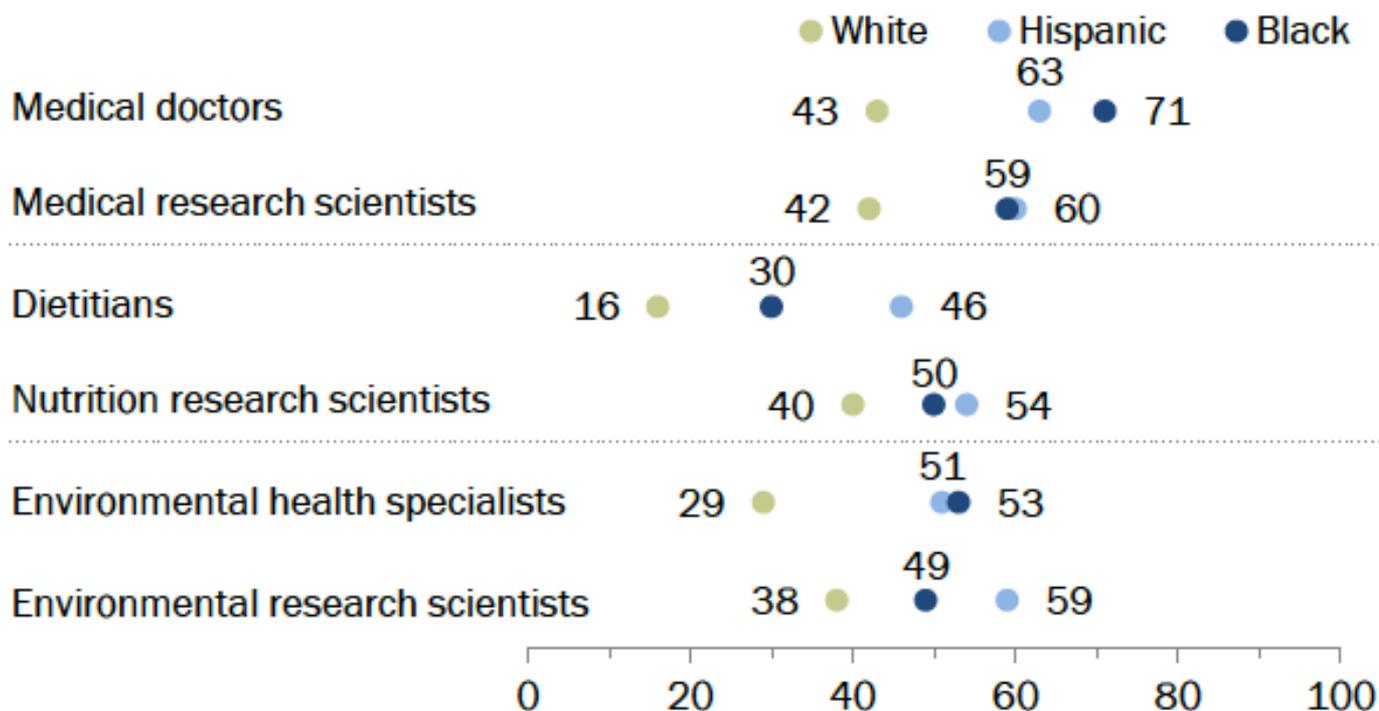
Note: Respondents who did not give an answer are not shown.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

## Blacks and Hispanics are more likely than whites to say scientific misconduct is a big problem

*% of U.S. adults who say professional or research misconduct by each of these groups is a very/moderately big problem*



Note: Respondents who gave other responses or who did not give an answer are not shown. Whites and blacks include those who report being only one race and are non-Hispanic. Hispanics are of any race.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

# Misadventures in Medical Practice and Research



# Experimentation on Slaves



- J. Marion Sims
  - “Father of modern gynecology”
  - Perfected surgical techniques by operating on 12 enslaved black women (1845-49).
  - Prime example of progress in the medical profession made at the expense of a vulnerable population.

# Nazi Human Experimentation



# Holmesburg Prison



# U. S. Public Health Service Syphilis Study at Tuskegee



# Overview of the Tuskegee Study

- Design: Prospective Observational Study
- Sample: 400 sharecroppers with syphilis
- Duration: 1932-1972
- Study aim: To document the natural history of disease in African American men to determine racial differences in the clinical manifestations of syphilis.

# Recruitment strategies

- Grass roots recruitment strategies
- Collaboration with a historically Black university
- A respected African American community member was a key recruiter of subjects
- Churches and schools were data collection sites
- Collaboration with plantation owners

# Legacy of the U. S. Public Health Service Syphilis Study at Tuskegee

- Symbol of mistreatment by the medical establishment, metaphor for deceit and conspiracy
- Noted in the scientific literature as a deterrent to African Americans' participation in health studies
- Implications for the prevention and treatment of HIV/AIDS
- Belief regarding institutional genocidal intentions

# Other Misadventures with Racial Minorities

- Court-ordered medical procedures (*Kolder, Gallagher, & Parsons, 1987*)
- Sickle-cell screening without knowledge or consent (*Farfel & Holtzman, 1984*)
- Non-consenting sterilization of African American women (*Aptheker, 1974*)
- Use of placebo birth control pills with Mexican American women (*Shavers-Hornaday et al., 1997*)

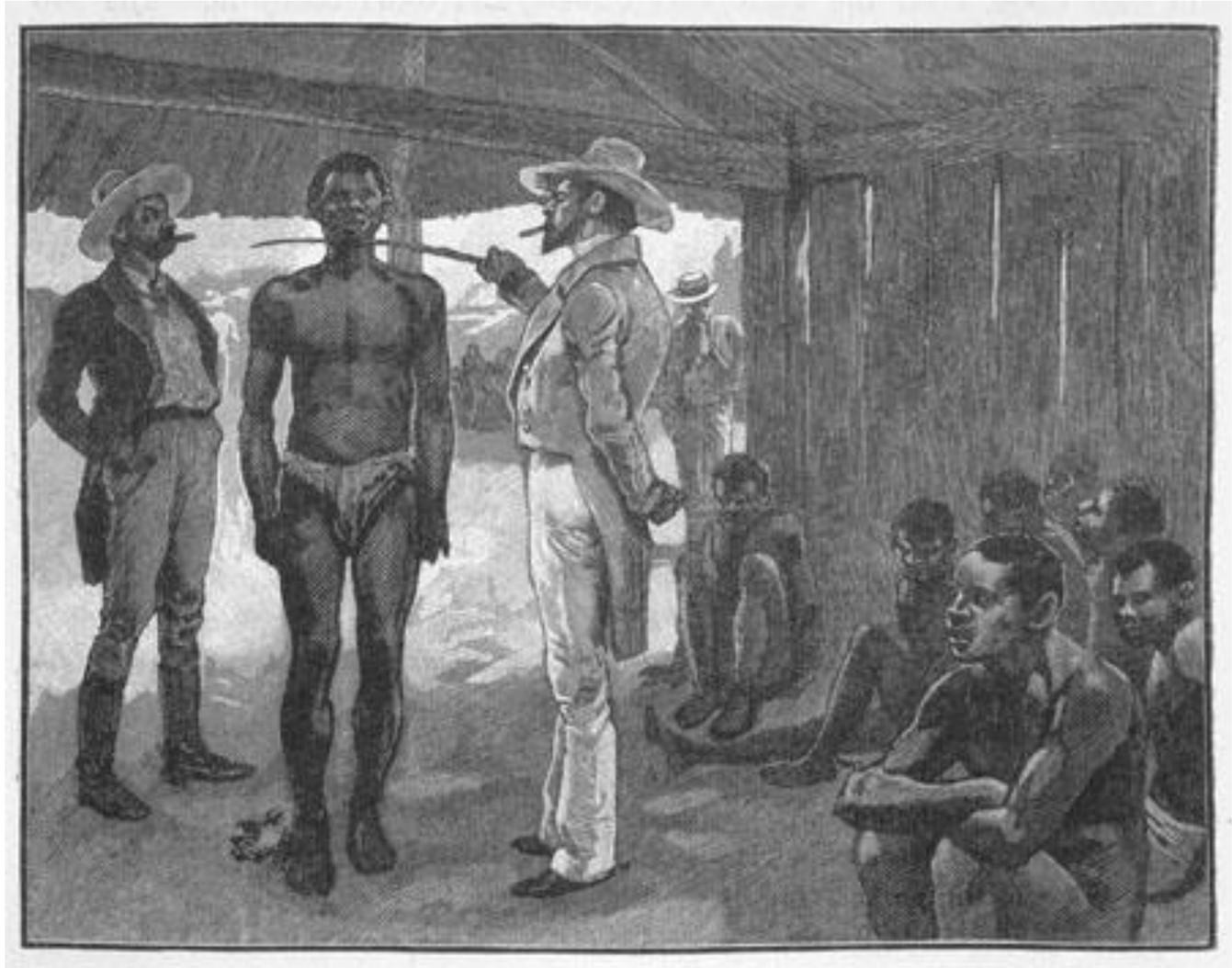
# Henrietta Lacks

- Came to Johns Hopkins for treatment
- Tissue obtained for research purposes without consent.
  - Immortalized cell lines were created from tissue
    - Immortalized cells are reproduced under certain conditions.
  - Cell lines are still used in research today.



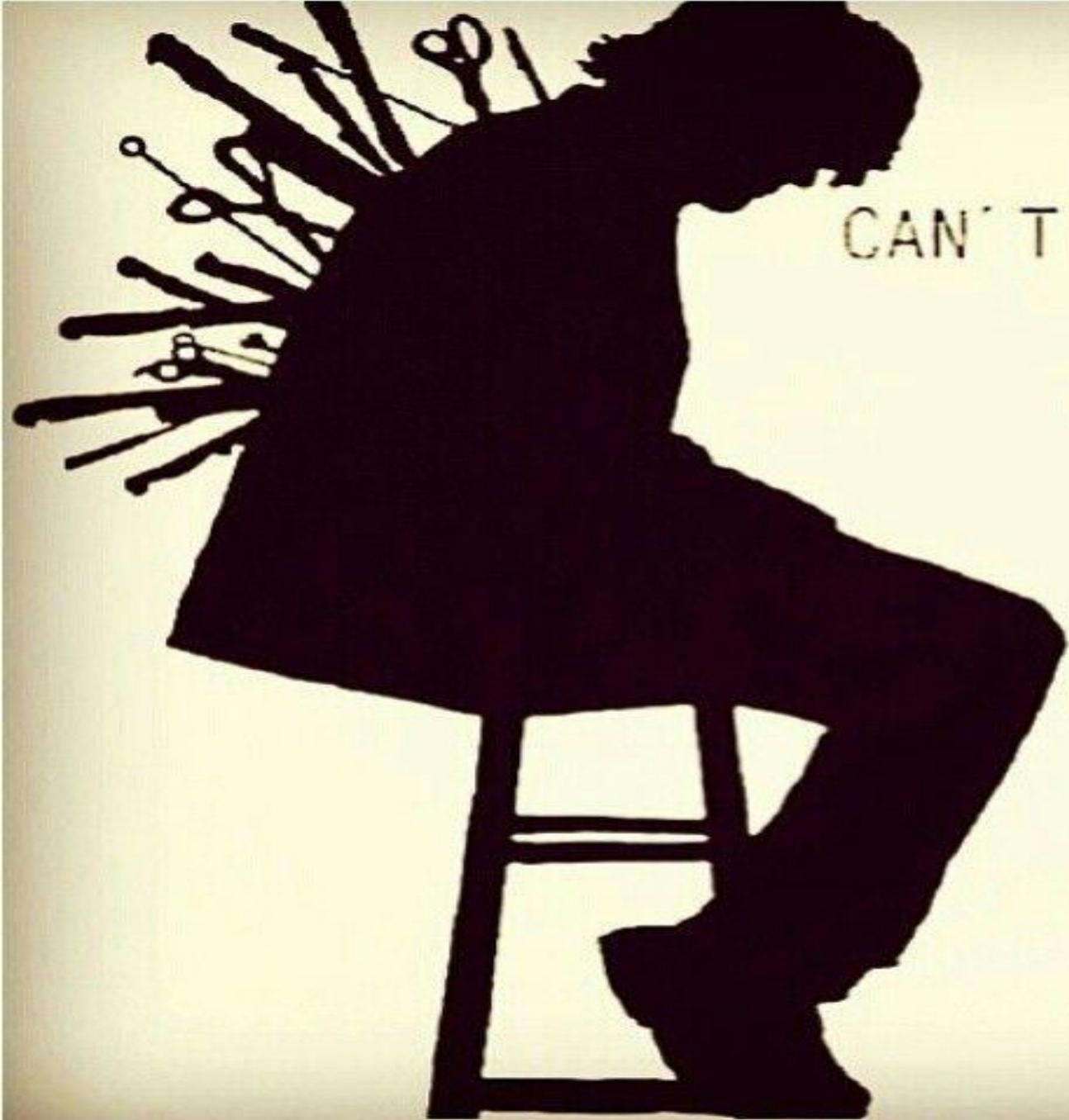
“THE REASON HENRIETTA'S CELLS WERE SO PRECIOUS WAS BECAUSE THEY ALLOWED SCIENTISTS TO PERFORM EXPERIMENTS THAT WOULD HAVE BEEN IMPOSSIBLE WITH A LIVING HUMAN.”

# How could this happen?



# How could this happen?



A black silhouette of a person sitting on a stool, leaning forward. From the back of the person, a large number of surgical instruments, including scalpels, forceps, and scissors, are protruding outwards, symbolizing a 'trust issue' in a medical or professional context.

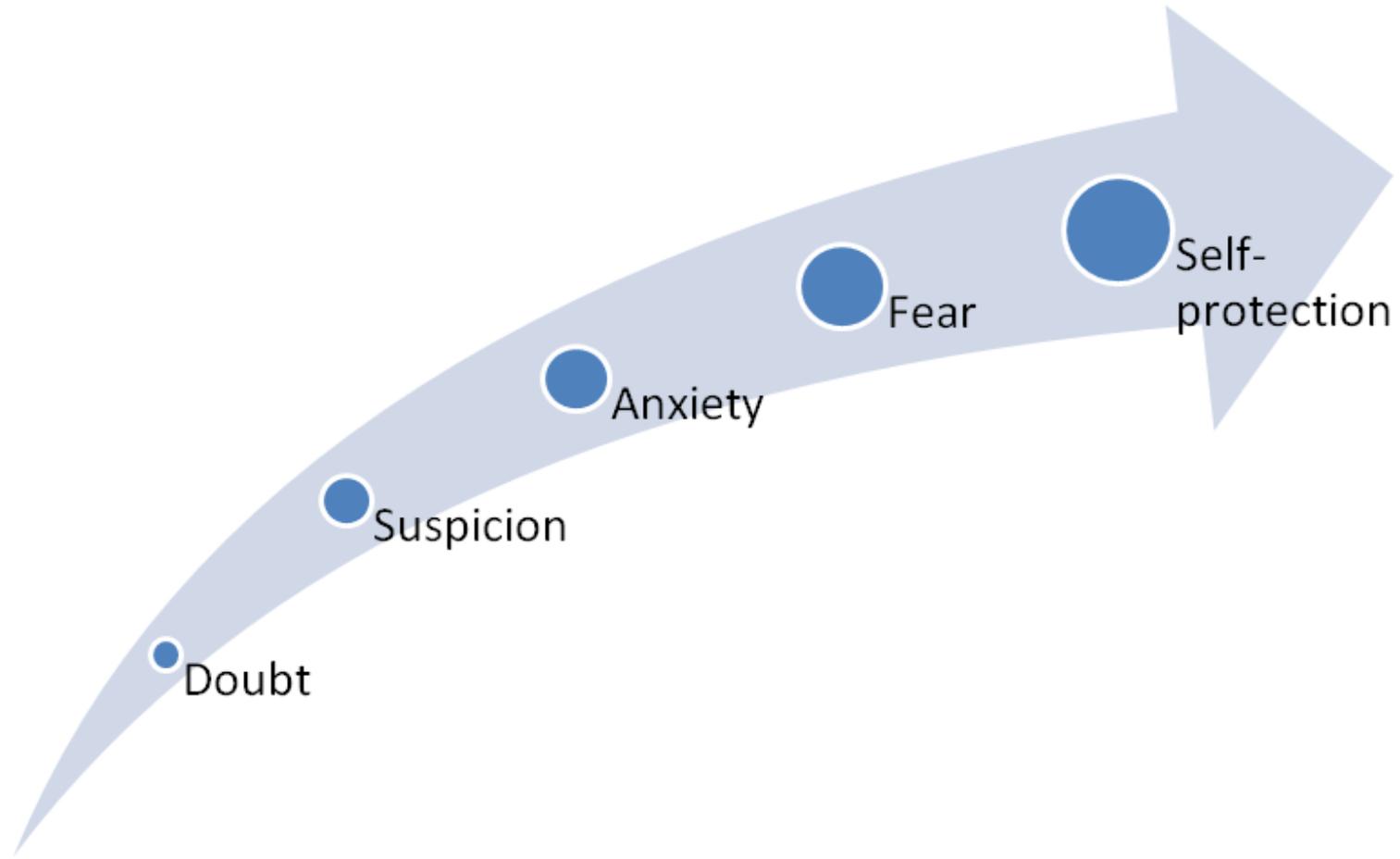
CAN'T BLAME ME  
FOR MY  
TRUST  
ISSUE

REPAIRERS

OF THE

BREACH

# Stages of Distrust







# Effective Engagement Requires Trust and Being Trustworthy

*Consuelo H. Wilkins, MD, MSCI*

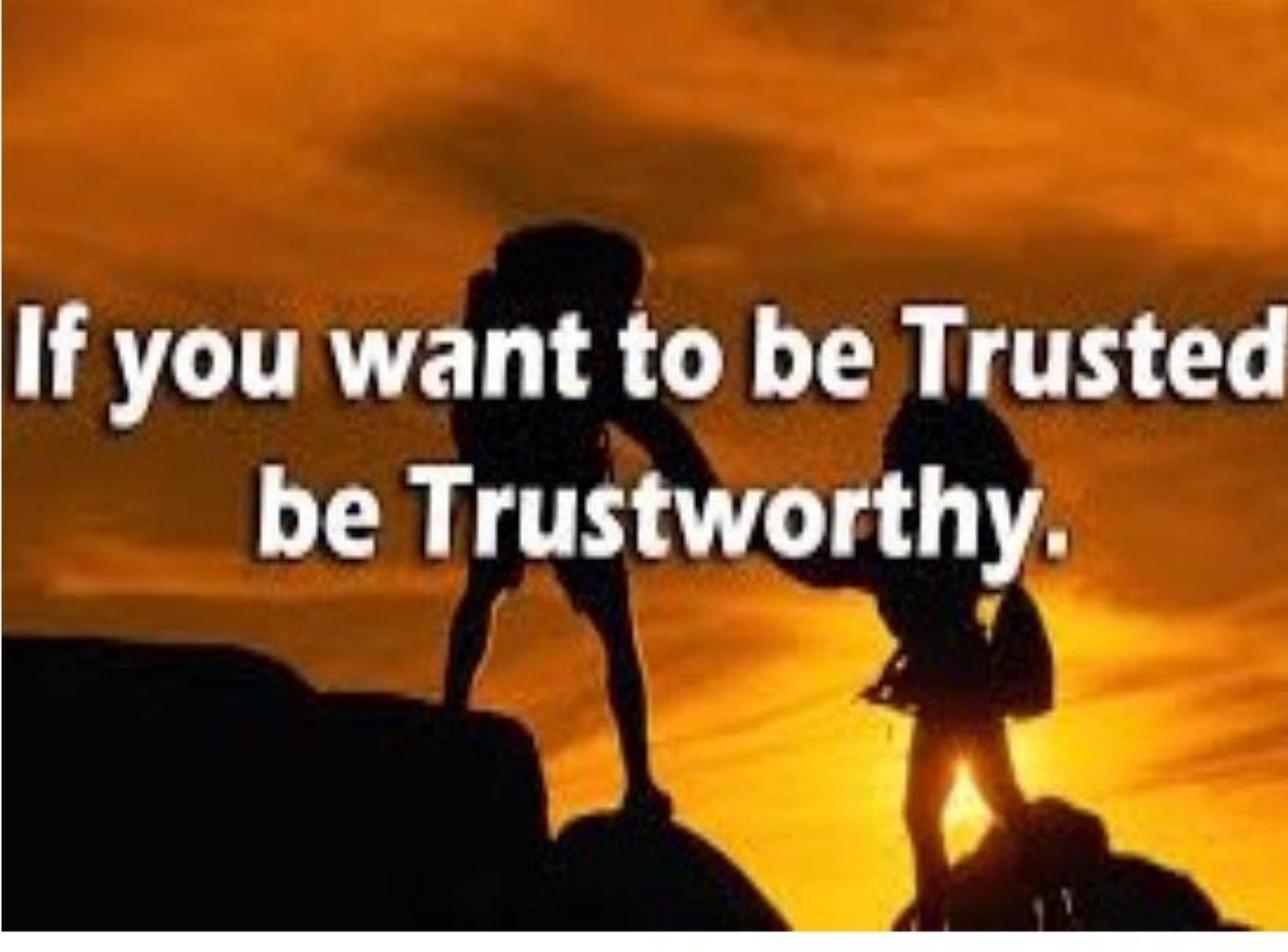
Trust is essential to building and maintaining mutually respectful relationships, especially partnerships involving patients or community stakeholders and researchers, in which there is often an inherent imbalance of power. Patients and community members who are stakeholders in the design and conduct of health research rely on researchers' honesty and willingness to protect them from harm. Although human research protections are in place for research participants, no such institutional protections are in place to provide oversight for patients and community partners involved in the research. Such vulnerability leads to lack of trust, which remains one of the most commonly cited barriers to public participation in research, especially among groups underrepresented in research.<sup>1</sup> As public involvement in research continues to evolve, the types of relationships with researchers have changed from being participants in research projects to being consultants, advisory board members, and even patient and community principal investigators. These new roles and increasing power for stakeholders have not diminished the importance of trust. Instead, the need for trust is perhaps more important as patients and community members must navigate less familiar research settings and must depend on researchers to share resources, leadership, and decision-making.

The critical role of trust in public engagement is evident in publications emerging from newer approaches to engagement such as those used in the National Patient-Centered Clinical Research Network (PCORnet). The NYC Clinical Data Research Network modified its engagement strategies to facilitate involvement of people with limited trust and found lack of trust to be associated with concerns about data privacy and security, and lack of confidence that findings would be shared with the community.<sup>2</sup> Within PCORnet, most networks identified trust as essential to achieving high levels of engagement and the need to build and nurture trust was clear.<sup>3</sup> The recurring themes of trust and trustworthiness in public engagement also highlights the gap in our knowledge related to the underpinnings of trust in community-academic relationships, the need to measure, track, and improve trust, and the responsibility of researchers to become more trustworthy.

If building trust is widely recognized as essential to engagement, why after decades of community engagement in research, does trust remain so elusive? One challenge is its complexity. Trust is a multidimensional construct and though the term is used often, many people find it difficult to define. In general, trust refers to a firm belief in the reliability, truth, and ability or strength of someone or something.<sup>4</sup> Trust has also been defined as the willingness to be vulnerable to the actions of another party, irrespective of the ability to monitor or control the other party.<sup>5</sup> An individual may have trust in a specific researcher or abstract trust in the research enterprise. There are a number of factors that influence an individual's level of trust in research including educational attainment, cultural beliefs, and personal as well as their community's experiences with research. Despite its importance, little is known about strategies to improve trust among research participants and we are only

# Trustworthiness

- Trait of deserving trust or confidence
- Characteristics that support or inspire trust
  - Ability
  - Benevolence
  - integrity

The image features a warm, golden sunset background. In the foreground, the dark silhouettes of two people are visible. One person stands on a rock on the left, while another person stands on a rock on the right, leaning forward. The overall mood is contemplative and serene.

**If you want to be Trusted  
be Trustworthy.**

# Being Trustworthy

- Engage in the relationship
  - Be present
  - Pay attention
- Commit to the multiple forms of learning
  - Group level
  - Individual level
- Recognize the challenges
  - Change and growth can be uncomfortable



**Trust =  $\frac{\text{consistency}}{\text{time}}$**

[ConversationAgent.com](http://ConversationAgent.com)

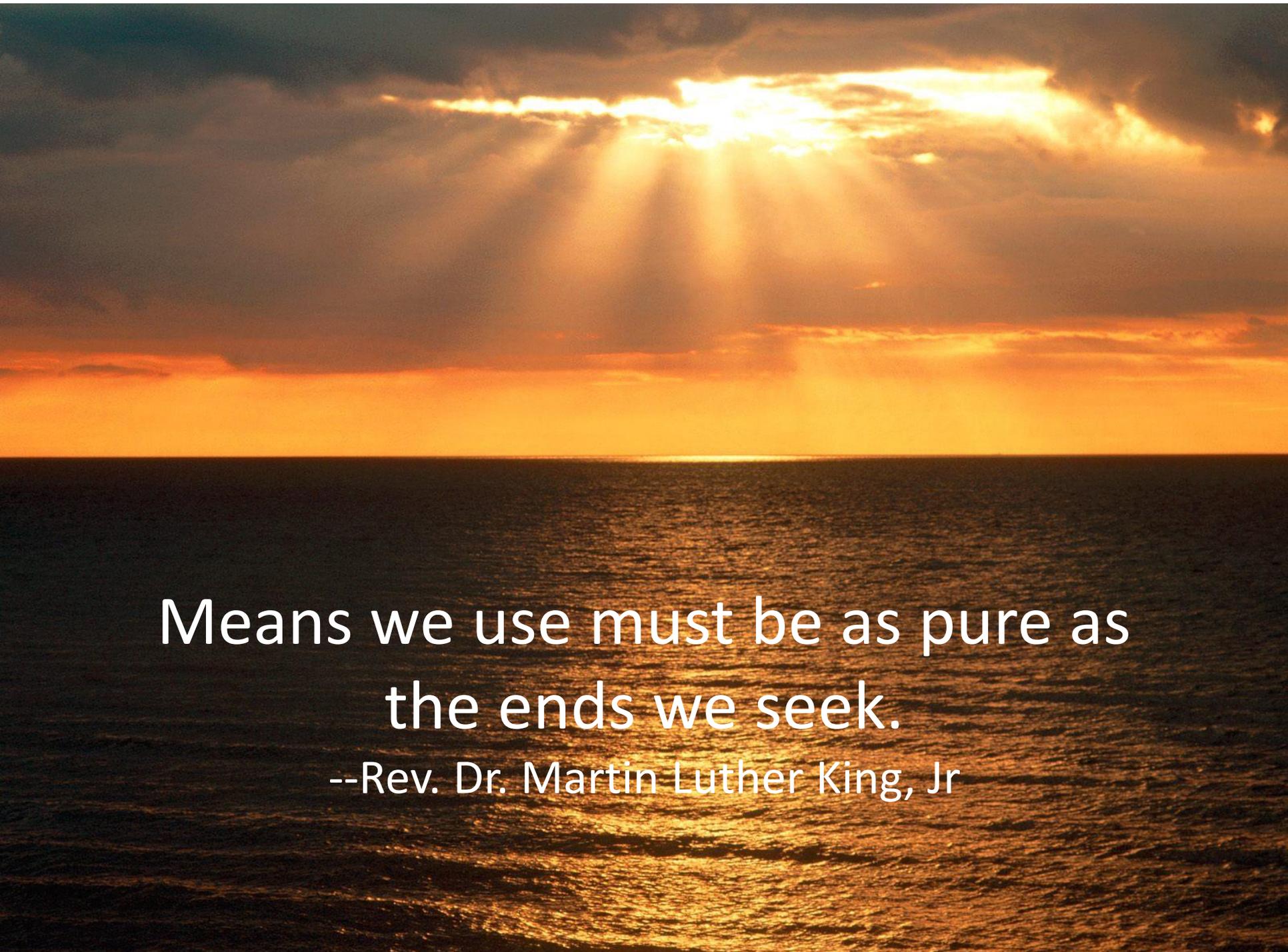
**WHETHER IT'S  
FRIENDSHIP OR  
RELATIONSHIP,  
ALL BONDS  
ARE BUILT ON  
TRUST.  
WITHOUT IT,  
YOU HAVE  
NOTHING.**

*Your tango*

# TRUST

"Trust is the glue of life. It's the most essential ingredient in effective communication. It's the foundational principle that holds all relationships."

- Stephen R. Covey

A dramatic sunset over the ocean. The sun is partially obscured by a thick layer of dark, heavy clouds, with bright rays of light breaking through and illuminating the scene. The sky transitions from a deep orange near the horizon to a darker, almost black at the top. The ocean below is dark, with the sun's light reflecting off the water's surface, creating a shimmering path of light. The overall mood is one of hope and transcendence.

Means we use must be as pure as  
the ends we seek.

--Rev. Dr. Martin Luther King, Jr