Trustworthiness

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

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• No disclosures

• No conflicts of interest

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  – Senior Pastor Reginald M. Buckley
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.
Mistrust

• Lack of trust based on feelings or instinct
• Feeling uneasy about someone or something
Era of Distrust and Mistrust
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

<table>
<thead>
<tr>
<th>Category</th>
<th>All or most of the time</th>
<th>Some of the time</th>
<th>Only a little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members of Congress</td>
<td>17%</td>
<td>64%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>NET all or most/some: 81%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET Only a little/no: 18%</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Journalists</td>
<td>15%</td>
<td>51%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Leaders of technology companies</td>
<td>12%</td>
<td>65%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>NET all or most/some: 77%</td>
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<tr>
<td>NET Only a little/no: 22%</td>
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<td></td>
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<tr>
<td>Religious leaders</td>
<td>10%</td>
<td>59%</td>
<td>25%</td>
<td>4%</td>
</tr>
<tr>
<td>NET all or most/some: 69%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET Only a little/no: 29%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Police officers</td>
<td>9%</td>
<td>52%</td>
<td>34%</td>
<td>4%</td>
</tr>
<tr>
<td>NET all or most/some: 61%</td>
<td></td>
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</tr>
<tr>
<td>NET Only a little/no: 38%</td>
<td></td>
<td></td>
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<tr>
<td>Military leaders</td>
<td>8%</td>
<td>42%</td>
<td>42%</td>
<td>6%</td>
</tr>
<tr>
<td>NET all or most/some: 50%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET Only a little/no: 48%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local elected officials</td>
<td>6%</td>
<td>60%</td>
<td>28%</td>
<td>4%</td>
</tr>
<tr>
<td>NET all or most/some: 66%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET Only a little/no: 32%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K-12 public school principals</td>
<td>6%</td>
<td>46%</td>
<td>40%</td>
<td>5%</td>
</tr>
<tr>
<td>NET all or most/some: 52%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET Only a little/no: 46%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Those who declined to answer are not shown.
“Why Americans Don’t Fully Trust Many Who Hold Positions of Power and Responsibility”
PEW RESEARCH CENTER
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?

<table>
<thead>
<tr>
<th></th>
<th>Members of Congress</th>
<th>Leaders of technology companies</th>
<th>Journalists</th>
<th>Religious leaders</th>
<th>Local elected officials</th>
<th>Police officers</th>
<th>Military leaders</th>
<th>K-12 public school principals</th>
</tr>
</thead>
<tbody>
<tr>
<td>None of the time</td>
<td>21%</td>
<td>16</td>
<td>13</td>
<td>13</td>
<td>9</td>
<td>10</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Only a little of the time</td>
<td>50%</td>
<td>42</td>
<td>40</td>
<td>40</td>
<td>32</td>
<td>35</td>
<td>34</td>
<td>29</td>
</tr>
<tr>
<td>Some of the time</td>
<td>21%</td>
<td>31</td>
<td>32</td>
<td>32</td>
<td>35</td>
<td>34</td>
<td>40</td>
<td>38</td>
</tr>
<tr>
<td>All or most of the time</td>
<td>4%</td>
<td>6</td>
<td>10</td>
<td>9</td>
<td>9</td>
<td>17</td>
<td>9</td>
<td>17</td>
</tr>
</tbody>
</table>

Face consequences none or only little of time: 71%  NET some/all or most of the time: 26

Note: Those who declined to answer are not shown.
“Why Americans Don’t Fully Trust Many Who Hold Positions of Power and Responsibility”

PEW RESEARCH CENTER
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

- Care about the people they represent
  - BLACK: 57%
  - WHITE: 72%

- Do a good job promoting laws and policies that serve the public interest
  - BLACK: 52%
  - WHITE: 68%

- Handle resources available to them in a responsible way
  - BLACK: 56%
  - WHITE: 65%

- Provide fair and accurate information to the public
  - BLACK: 52%
  - WHITE: 68%

- Admit mistakes and take responsibility for them
  - BLACK: 36%
  - WHITE: 43%

“Why Americans Don’t Fully Trust Many Who Hold Positions of Power and Responsibility”

PEW RESEARCH CENTER
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”

PEW RESEARCH CENTER
The public is divided over whether misconduct by medical professionals is a big problem

<table>
<thead>
<tr>
<th></th>
<th>Very big problem</th>
<th>Moderately big problem</th>
<th>Small problem</th>
<th>Not a problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical doctors</td>
<td>15</td>
<td>35</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical research scientists</td>
<td>14</td>
<td>34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental research scientists</td>
<td>13</td>
<td>29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition research scientists</td>
<td>12</td>
<td>31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental health specialists</td>
<td>10</td>
<td>26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietitians</td>
<td>6</td>
<td>18</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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”

PEW RESEARCH CENTER
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 ...

<table>
<thead>
<tr>
<th></th>
<th>All/most of the time</th>
<th>Some of the time</th>
<th>Only a little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition research scientists</td>
<td></td>
<td></td>
<td></td>
<td>41</td>
</tr>
<tr>
<td>Dietitians</td>
<td></td>
<td></td>
<td></td>
<td>36</td>
</tr>
<tr>
<td>Environmental research scientists</td>
<td></td>
<td></td>
<td></td>
<td>36</td>
</tr>
<tr>
<td>Medical research scientists</td>
<td></td>
<td></td>
<td></td>
<td>38</td>
</tr>
<tr>
<td>Environmental health specialists</td>
<td></td>
<td></td>
<td></td>
<td>32</td>
</tr>
<tr>
<td>Medical doctors</td>
<td></td>
<td></td>
<td></td>
<td>27</td>
</tr>
</tbody>
</table>

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”

PEW RESEARCH CENTER
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

<table>
<thead>
<tr>
<th>Professional/Research Group</th>
<th>White</th>
<th>Hispanic</th>
<th>Black</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical doctors</td>
<td>43</td>
<td>63</td>
<td>71</td>
</tr>
<tr>
<td>Medical research scientists</td>
<td>42</td>
<td>59</td>
<td>60</td>
</tr>
<tr>
<td>Dietitians</td>
<td>16</td>
<td>30</td>
<td>46</td>
</tr>
<tr>
<td>Nutrition research scientists</td>
<td>40</td>
<td>50</td>
<td>54</td>
</tr>
<tr>
<td>Environmental health specialists</td>
<td>29</td>
<td>51</td>
<td>53</td>
</tr>
<tr>
<td>Environmental research scientists</td>
<td>38</td>
<td>49</td>
<td>59</td>
</tr>
</tbody>
</table>

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”

PEW RESEARCH CENTER
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?
CAN'T BLAME ME FOR MY TRUST ISSUE
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.\(^1\) 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.\(^2\) Within PCORnet, most networks identified trust as essential to achieving high levels of engagement and the need to build and nurture trust was clear.\(^3\) 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.\(^4\) 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.\(^5\) 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
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{consistency}{time}
WHETHER IT’S FRIENDSHIP OR RELATIONSHIP, ALL BONDS ARE BUILT ON TRUST. WITHOUT IT, YOU HAVE NOTHING.
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
Means we use must be as pure as the ends we seek.

--Rev. Dr. Martin Luther King, Jr