Approaches to earning and sustaining trust in healthcare

Where are we and where do we want to go?

UNIVERSITY OF MICHIGAN

2023 Healthcare Safety Conference
University of Texas
Commons Conference Center
August 23-24

Goals

- Current state of trust and why it matters
- What conclusions can we draw from last decades of scholarship in trust to inform future studies and practice?
- A framework for evaluating trust in an organization

Trust matters

COVER

Resistance to science

Crisis of confidence sparks global debate on how to respond to attacks on science

https://revistapesquisa.fapesp.br/en/resistance-to-science/

THE TEXAS TRIBUNE

INVESTIGATIONS NEWSLETTERS EVENTS AUDIO

DONATE Paxton Impeachment New Laws STAAR Scores Texas Tribune Festival

TribBlog: DSHS Will Destroy Blood Spots

The Department of State Health Services will destroy all blood samples taken from infants before May 27, 2009 to settle a lawsuit over the state's newborn screening program.

BY EMILY RAMSHAW DEC. 22, 2009 1 PM CENTRAL SHARE REPUBLISH

https://www.texastribune.org/2009/12/22/dshs-will-destroy-blood-spots/

Tue, Dec 13, 2022 **Newsweek**

U.S. | World | Tech & Science | Culture | Autos | Rankings | Health | Life | Opinion | Experts | Education

OPINION

U.S. Health Care Faces A Crisis of Trust | Opinion

https://www.newsweek.com/us-health-care-faces-crisis-trust-opinion-1635658

This Issue Views 3,599 | Citations 8 | Altmetric 21

Viewpoint | Trust in Health Care

December 15, 2020

Patient Consumerism, Healing Relationships, and Rebuilding Trust in Health Care

Dhruv Khullar, MD, MPP[1,2]; Gwen Darien, BA[3]; Debra L. Ness, MS[4]

Author Affiliations | Article Information

JAMA. 2020;324(23):2359-2360. doi:10.1001/jama.2020.12938

https://jamanetwork.com/journals/jama/article-abstract/2774058

Shifting contexts: Expansion of health information technologies

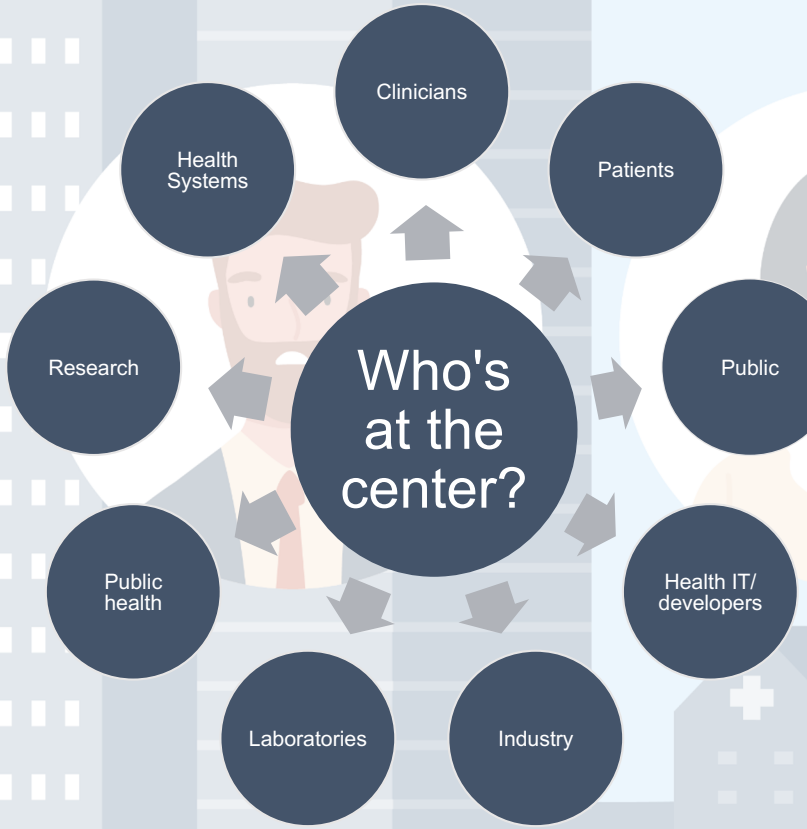
- EHR: In 10 years, hospitals: 78% → 96%
  - Office based physicians: 34% → 78% (ONC)
- 350,000 Consumer health apps (IQVIA, 2021)
- $$$ Spending billions of dollars $$$
- Data sharing: Increasing interoperability capabilities (ONC, 2020)
- Variation in capacity for advanced health analytics

Strains on policy frameworks

Old practice paradigm	New practice paradigm
Intended purpose (research, QI, clinical care, public health) ↓ Policy ↓ Collect data	Collect data ↓ Intended purpose (research, QI, clinical care, public health)

What are the appropriate policies? Where do we need to innovate? Where do existing structures work?

Strains on ethical frameworks



Multiple stakeholders/ actors

- Different values and ethical frames
- Differences in power and access
- Different scopes of work

Can we "center at the margins"?
(Ford and Airhenbuha, 2010)

Strains on structural equity

JAMA Network | Open

Original Investigation | Public Health

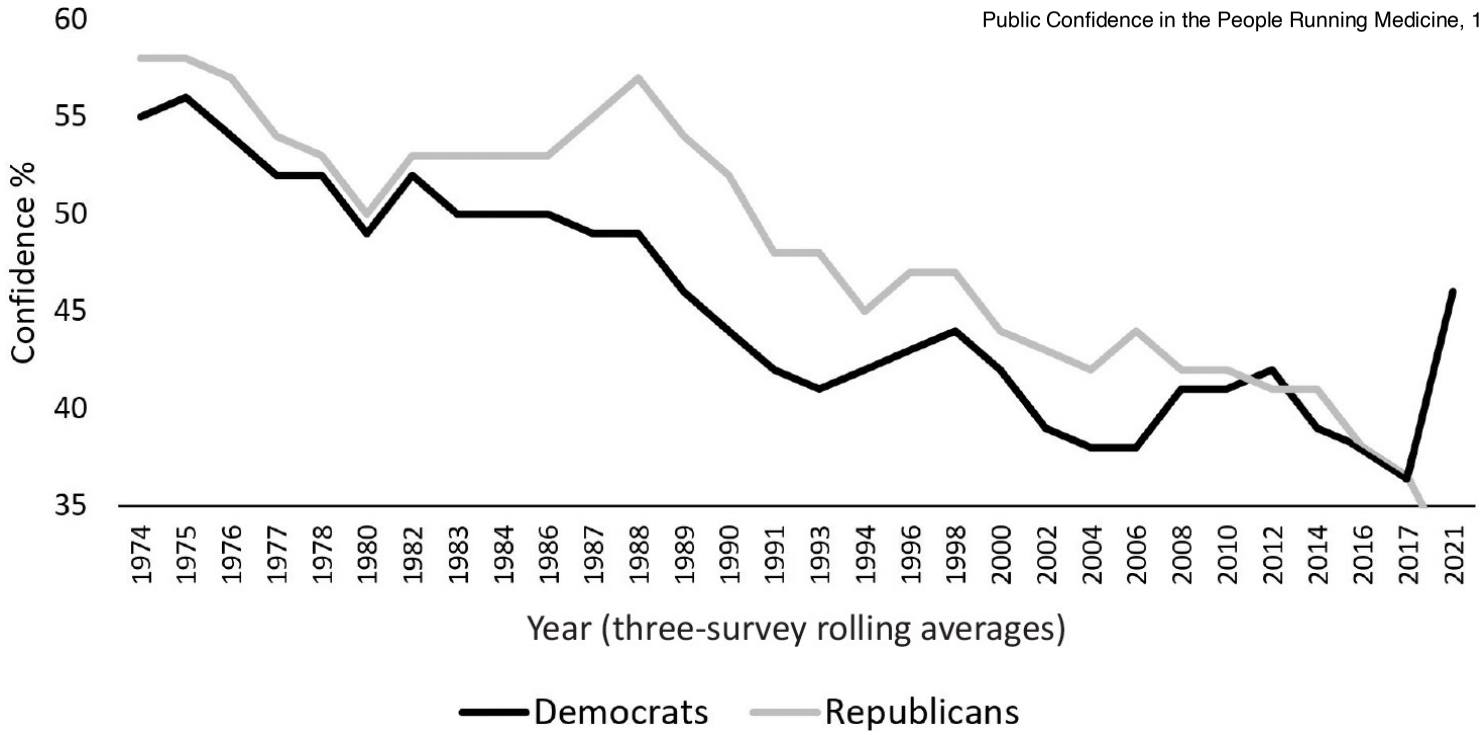
Patient-Reported Experiences of Discrimination in the US Health Care System

Paige Nong, BA; Minakshi Raj, PhD; Melissa Creary, PhD; Sharon L. R. Kardia, PhD; Jodyn E. Platt, PhD

~ 20% of the U.S. public reports experiencing discrimination when receiving health care

Strains on trust

Public Confidence in the People Running Medicine, 1973–2021



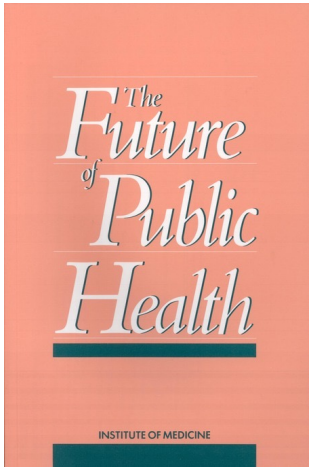
Blendon RJ, Benson JM. Trust in Medicine, the Health System & Public Health. Daedalus. 2022 Nov 15;151(4):67-82.

What is health policy?

Toby Citrin, JD, MPH

Decision making that shapes rules and action and that blends professional knowledge with community values

(paraphrase)



Policy problem

Are we creating systems that deserve the trust of people and populations?

How can we better align policy with public expectations and values?

Examining public comfort, values, and alignment with current policy

- Study 1: Is the public comfortable with data sharing?
- Study 2: Does current policy for data sharing (notification) align with public comfort?
- Study 3: Does it matter?

Research methods

- Surveys of general public (2016, 2019, 2021)
  - 2016 (GfK/ IPSOS) (n=1,014)
  - *2019 (NORC) (n= 2,060);* 2021 (NORC) (n= 1,541) *Longitudinal*
- Public deliberation in Michigan (2019-2021) (n=143)
  - 6 sessions; Patients (n=62), Community members (n=81)
- Funding
  - Life Cycle of Data Policies and Practices (NIH/ NCI 5R01CA214829-02); Public Trust of Artificial Intelligence in the Precision CDS Health Ecosystem (NIH/ NIBIB 1-RO1-EB030492-01)

Study 1: Is the public comfortable with being a part of information sharing networks?

Comfort with information sharing

I am comfortable having my electronic health information being part of a network that includes:

- Other health care providers involved in my care
- Research networks
- Quality improvement networks
- Mental health services
- All health care providers in my state
- Social service agencies

Platt J, Raj M, Büyüktür AG, Trinidad MG, Olopade O, Ackerman MS, Kardia S. Willingness to Participate in Health Information Networks with Diverse Data Use: Evaluating Public Perspectives. eGEMs. 2019;7(1).

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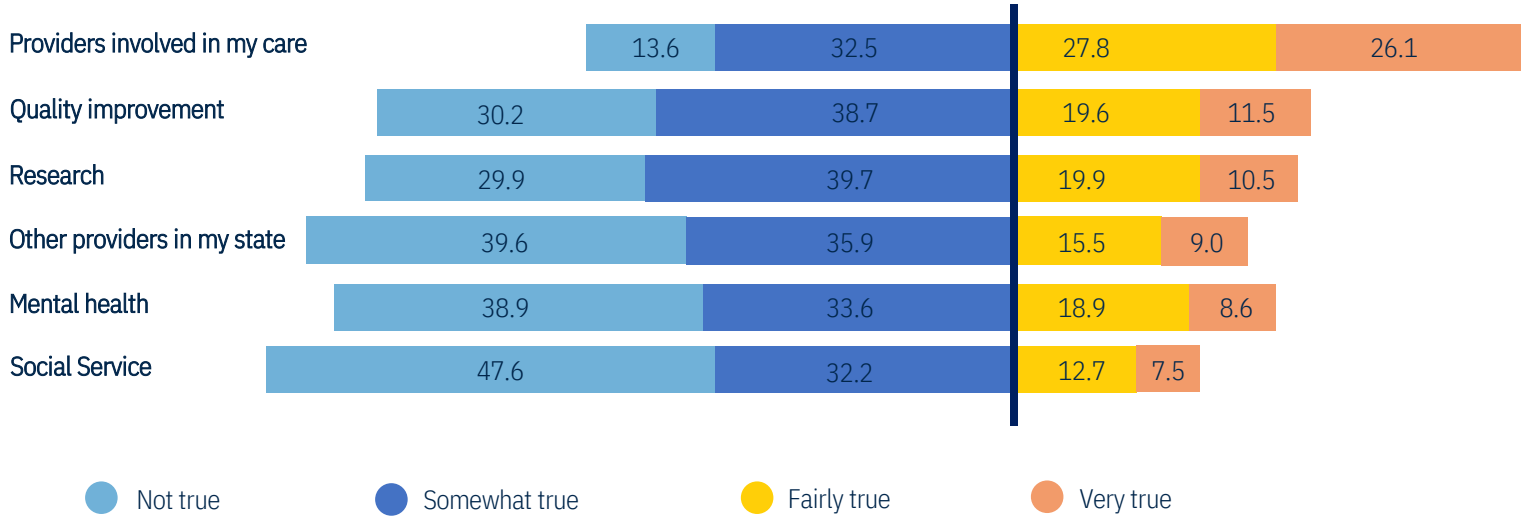

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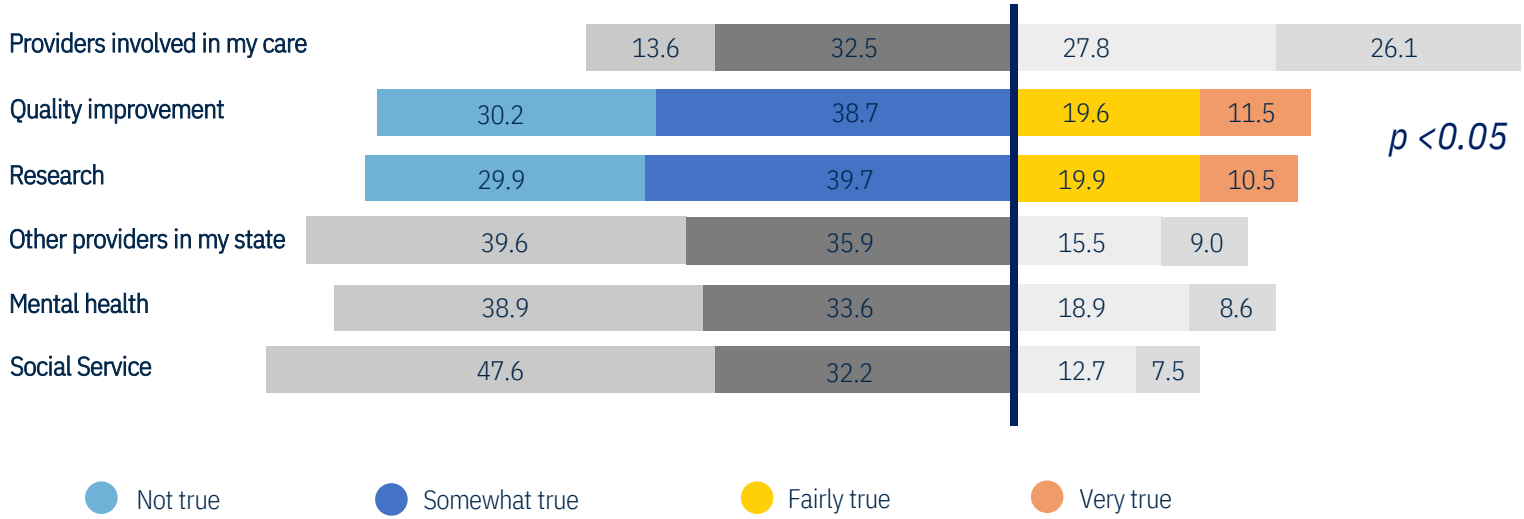

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Factors associated with comfort with information sharing networks[1]		b* (p value) $R^2 = 0.426$
Education	B.A. or higher	REF
	Some college	0.009 (0.773)
	High school or less	-0.110 (0.003)
Trust	Health System Trust Index (Range 4= low trust; 16 = high trust)	0.094 (0.033)
	Generalized Trust	0.081 (0.030)
Governance/ Obligation	Obligation to Participate in Research	0.217 (<0.001)
	Confidence in current governance (index) (Range: 1 = Low confidence; 4 = high confidence)	0.393 (<0.001)
Privacy	Privacy Index (Range: 1= low privacy concerns; 4 = high privacy concerns)	-0.276 (0.002)
	Privacy*My health insurer could use information against me (interaction term)	0.298 (0.030)
	My health insurer could use my information against me	-0.063 (0.470)
Permission	I would like to give permission for health information to be shared in a network	0.116 (0.001)
Notification	I would like to be notified if my health information is shared	-0.090 (0.012)

[1]Weighted OLS stepwise regression w/ Bonferroni correction; inclusion p=0.05/*k,* exclusion p=0.05; b*= Standardized beta coefficient.

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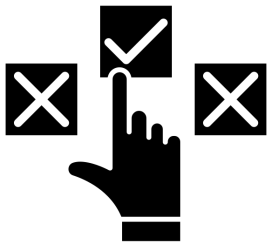
Is the public comfortable with being a part of information sharing networks?

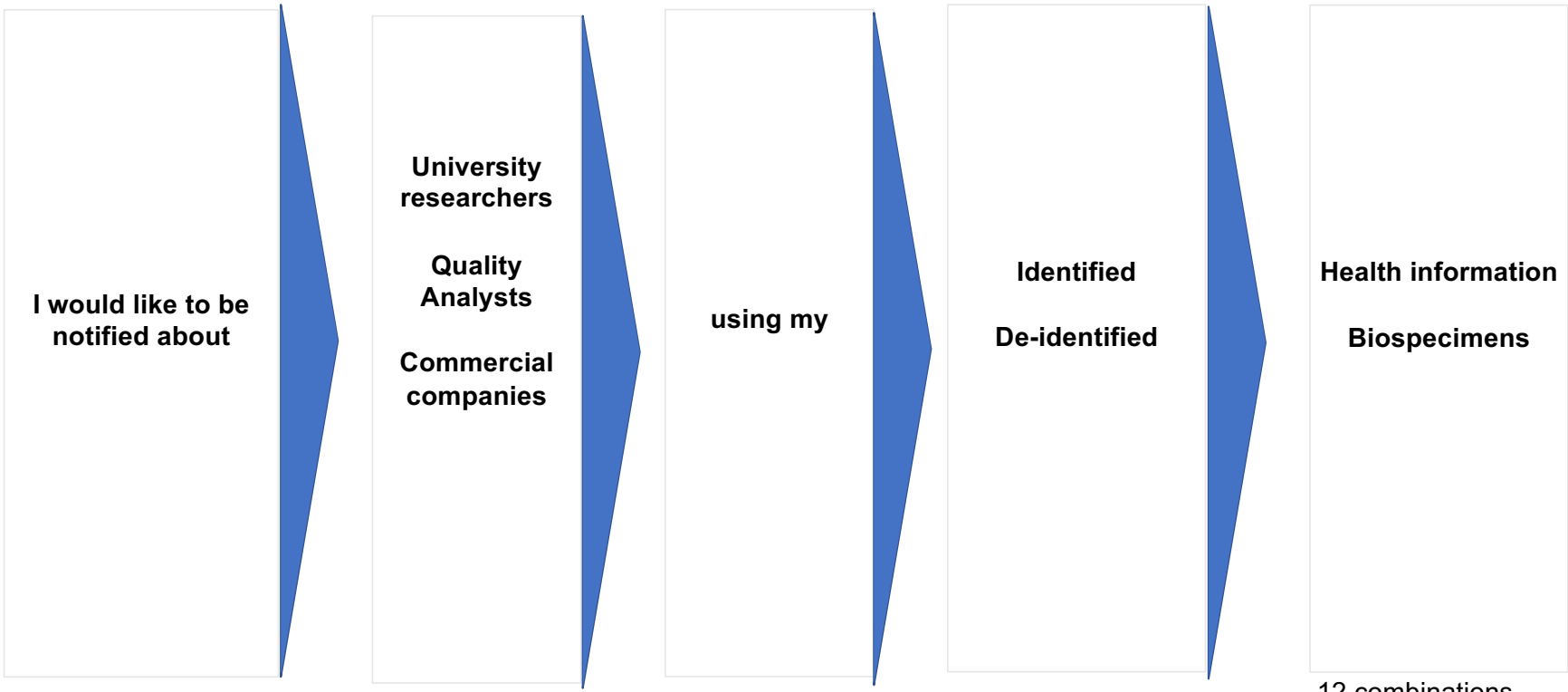
- Not really
- No distinction between quality improvement and research
- People who are more comfortable:
  - Higher levels of education
  - Higher confidence in governance; belief in obligation to participate in research
  - Higher levels of trust
  - Not concerned about harm
- Notification and consent are related to comfort

Study 2: Does current policy align with public comfort?



Preferences for notification

(NORC AmeriSpeak Panel (2019); n=2,157)



12 combinations

Spector-Bagdady K, Trinidad G, Kardia S, Krenz CD, Nong P, Raj M, Platt JE. Reported Interest in Notification Regarding Use of Health Information and Biospecimens. *JAMA*. 2022 Aug 2;328(5):474-6.

For you, how true are the following statements *I would like to be notified about [A] using my [B] [C].* (4-point Likert scale, Range: 1= Not True; 4= Very True)			Mean (Range 1-4)
A	B	C	
Commercial companies	Identified	Biospecimens	3.4
Commercial companies	De-identified	Biospecimens	2.9
Commercial companies	Identified	Health information	3.4
Commercial companies	De-identified	Health information	3.0
Quality Analysts	Identified	Biospecimens	3.3
Quality Analysts	De-identified	Biospecimens	2.7
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University researchers	Identified	Biospecimens	3.4
University researchers	De-identified	Biospecimens	2.8
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- **People would like to be notified about all uses/users**
- **Preference is stronger for identified v. de-identified**
- **No difference between QI and Research**
- **No difference between health information and biospecimens**

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*Midpoint = 2.5

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Study 3: Does it matter?

SSM - Population Health
Volume 18, June 2022, 101092

Discrimination, trust, and withholding information from providers: Implications for missing data and inequity

Paige Nong [a], Alicia Williamson [b], Denise Anthony [a], Jodyn Platt [c], Sharon Kardia [a]

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Sample demographics

Measure	Unweighted n	Weighted %
Sex		
Female	1036	48.2
Male	993	51.8
Age		
18-29	242	16.3
30-44	599	26.0
45-59	526	27.5
60+	662	30.2
Race/ethnicity		
White	1180	63.8
Black	321	11.9
Hispanic	396	15.8
Asian	48	3.8
Other	84	4.7

Discrimination and trust (n = 2,029)

Measure	Unweighted n	Weighted %
Ever withheld information from a provider		
Yes	**617**	**27.5**
No	**1519**	**72.5**
Experienced discrimination in the healthcare system		
Yes	425	19.1
No	1604	81.0
Low trust in providers' financial motivations		
Yes	357	17.8
No	1672	82.2
Low trust that providers disclose conflicts of interest		
Yes	774	37.5
No	1255	62.5
Low trust that providers use health information responsibly		
Yes	299	14.1
No	1730	85.9
Low trust in providers generally		
Yes	258	12.3
No	1771	87.7

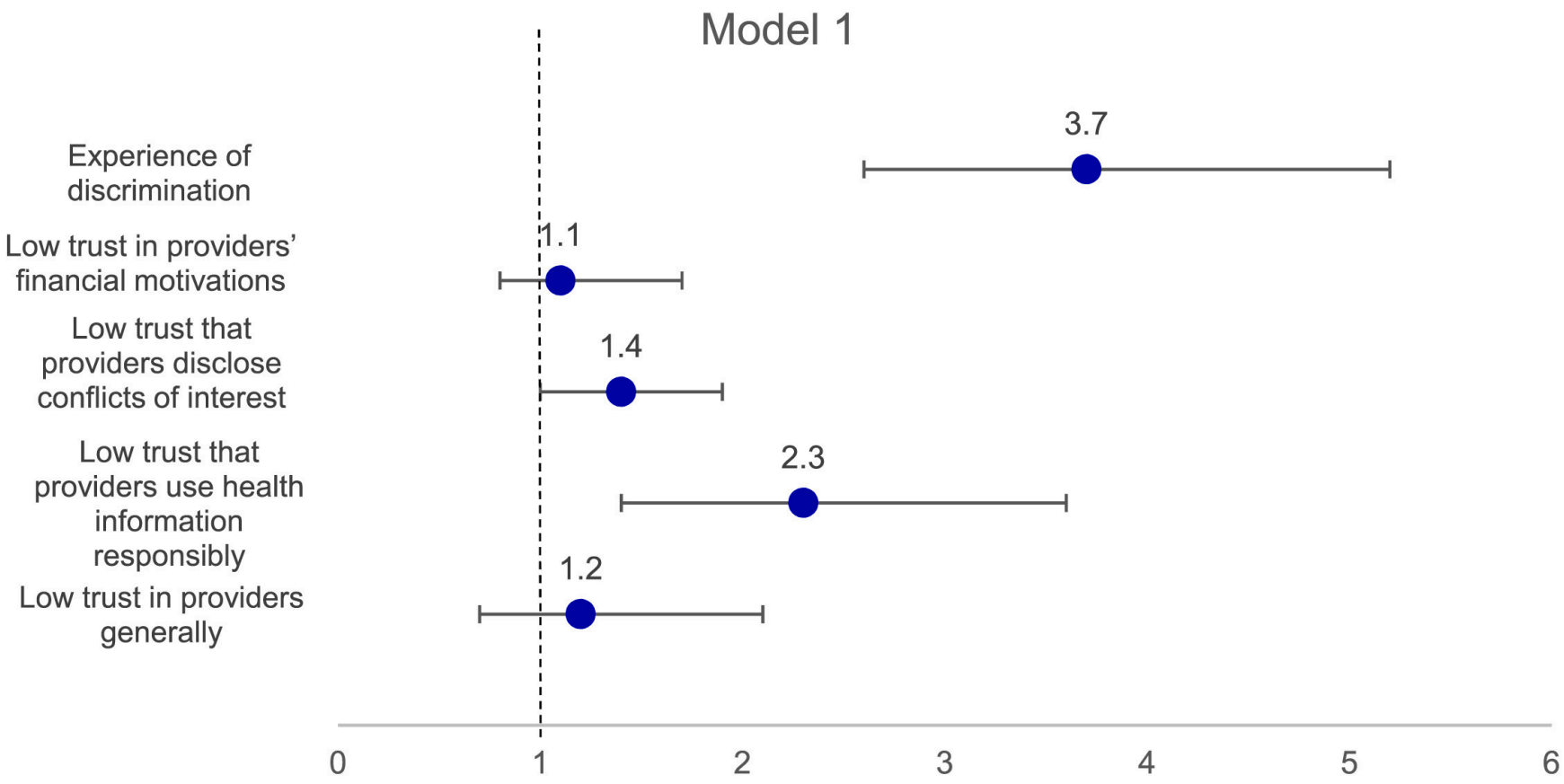


Fig. 1. Odds ratios [95% CI] from weighted multivariable logistic regression of withholding information from providers on experiences of discrimination and low trust in providers, (n = 2,029).

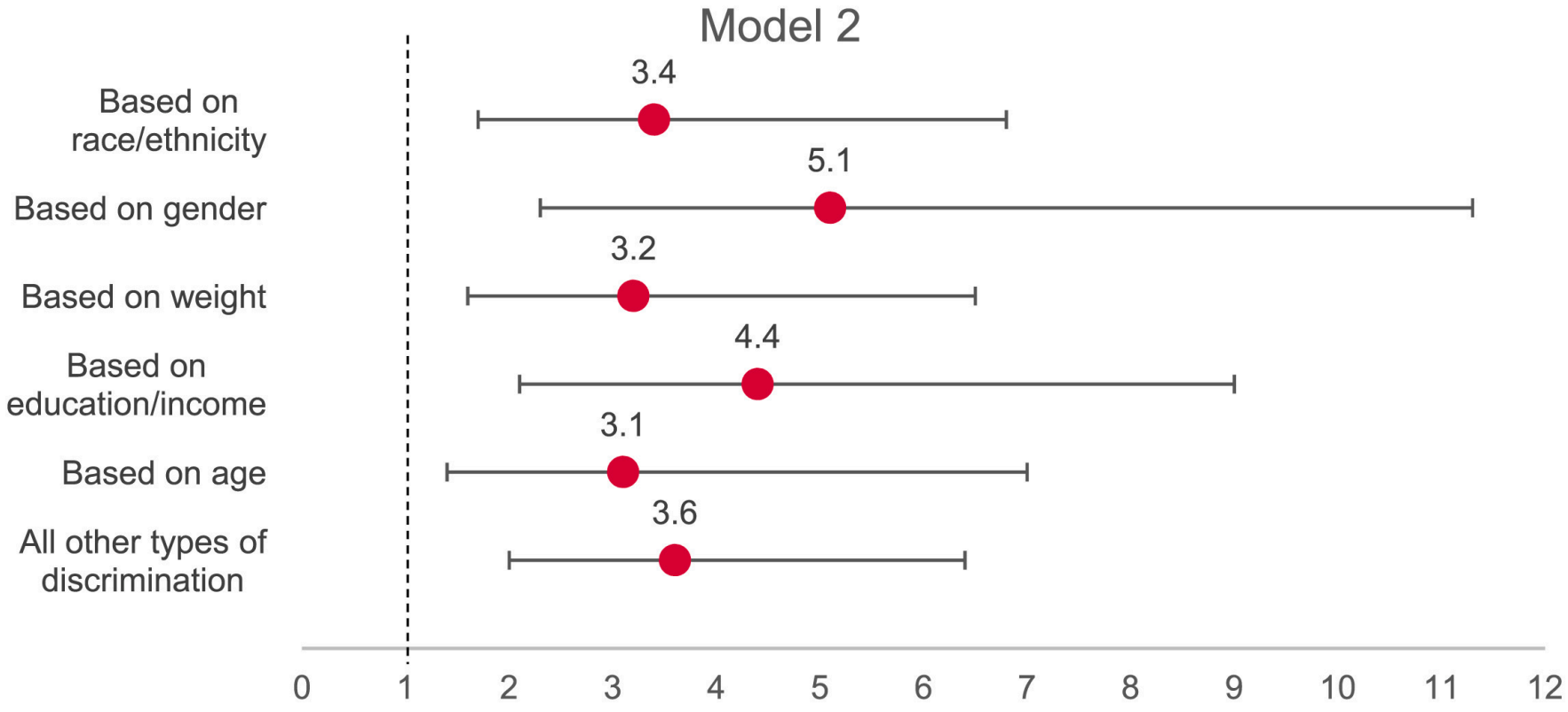


Fig. 2. Odds ratios [95% CI] from weighted multivariable logistic regression of withholding information from providers on five most common experiences of discrimination (n = 2,029).

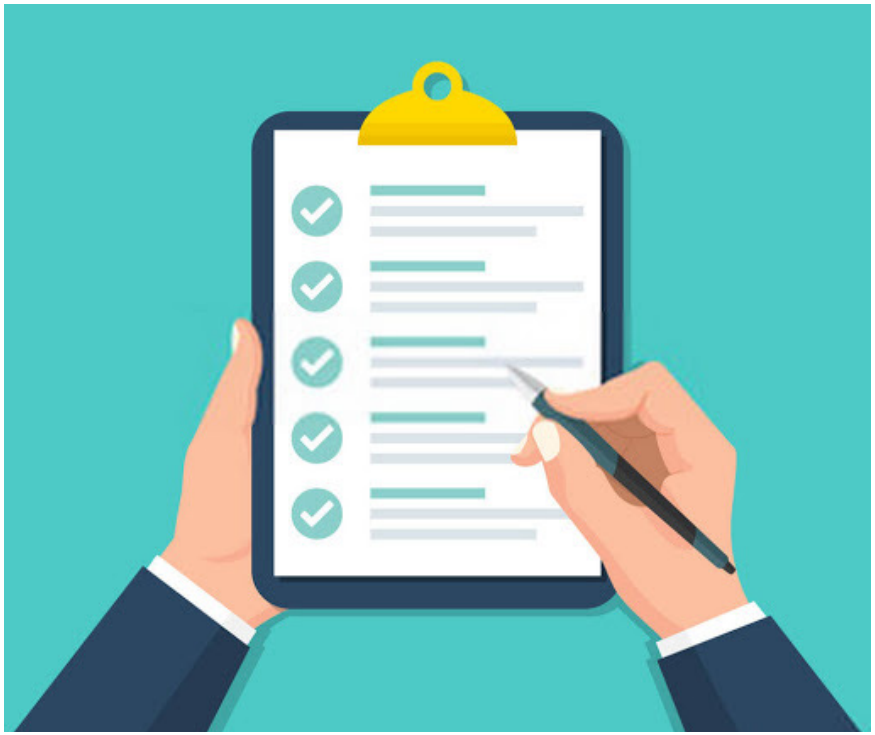
What do the three studies tell us?

- Inclusion and respect as mechanisms of trust
- Misalignment of policies for notification and public preferences
- Role for measuring and monitoring trust and inequity

Things we know about trust (and why it matters)

- Familiarity fosters trust (Luhmann, 2000; Meyer S, Ward P, Coveney J, Rogers W., 2008; Giddens 1991)
- Meeting (or exceeding) expectations fosters trust (Möllering, 2005; Hsu et al, 2007)
- Trust, Mistrust, and Distrust are based on experience (Griffith, 2020; Armstrong (var); LaVeist (var))
- Trust is relational, and dynamic (not a Field of Dreams) (Schilke, Reimann, Cook, 2021)
- Trust is multi-dimensional (e.g., competency, integrity, fidelity) (Hall, 2001; Platt et al. 2018, Raj, 2019)
- Related to risk, uncertainty, power, vulnerability, autonomy (Luhmann, Baier, Giddens, Hall)
- Trust provides a limited license

Synthesizing the literature



ifty Years of Trust Research in Health Care A Synthetic Review.pdf - Adobe Acrobat Reader (32-bit)

THE MILBANK QUARTERLY

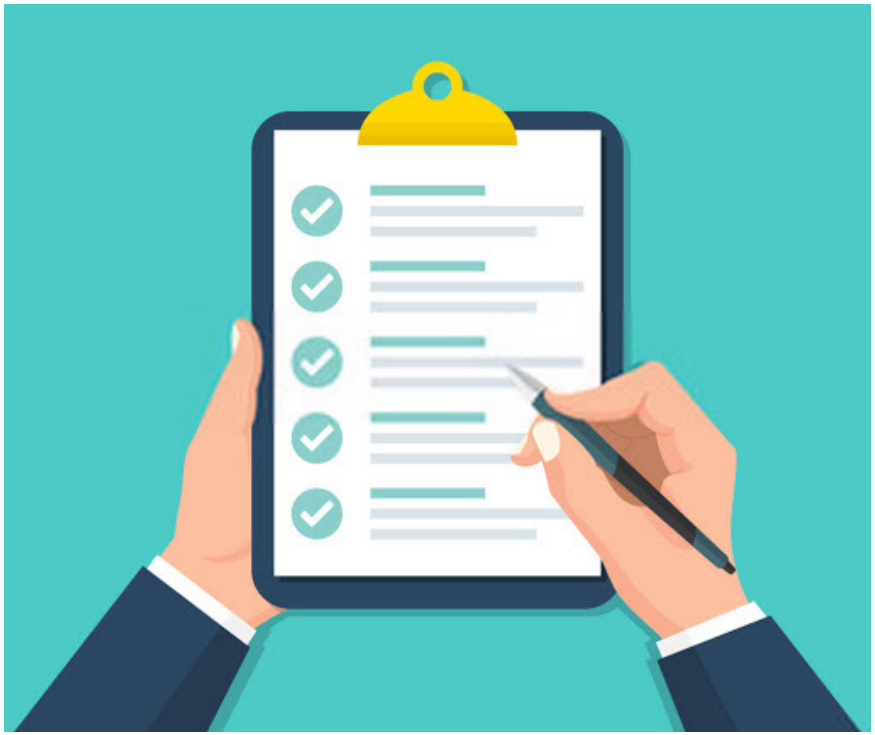
A MULTIDISCIPLINARY JOURNAL OF POPULATION HEALTH AND HEALTH POLICY

Fifty Years of Trust Research in Health Care: A Synthetic Review

LAUREN A. TAYLOR,* PAIGE NONG,† and JODYN PLATT‡

*NYU Grossman School of Medicine, New York, USA; †University of Michigan School of Public Health, Ann Arbor, USA; ‡University of Michigan Medical School, Ann Arbor, USA

Measuring trust: Can there be only one?



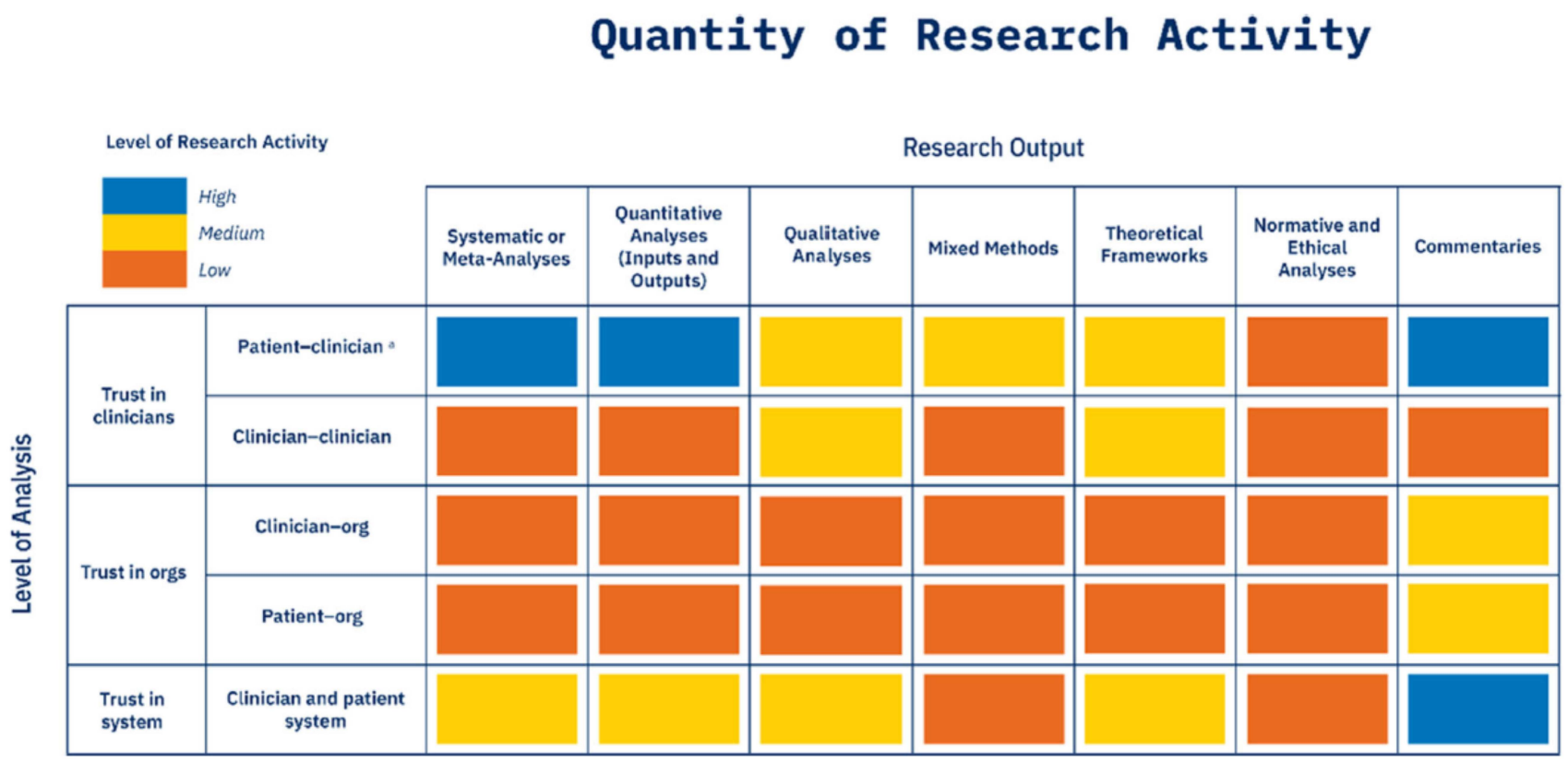
- Lack of consensus around single measure(s)
- Meaning of trust is contingent on context and on who is trusting whom

The use cases

https://academyhealth.org/about/programs/advancing-research-trust

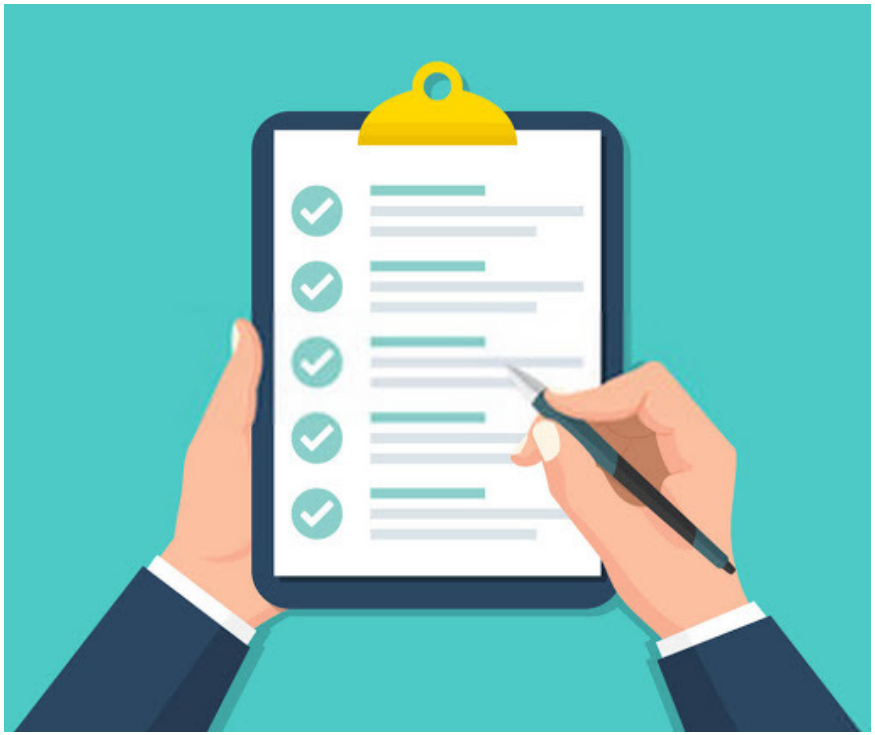
Attributes of trust

Figure 2. Quantity of Research Activity Among Trust Subliteratures.



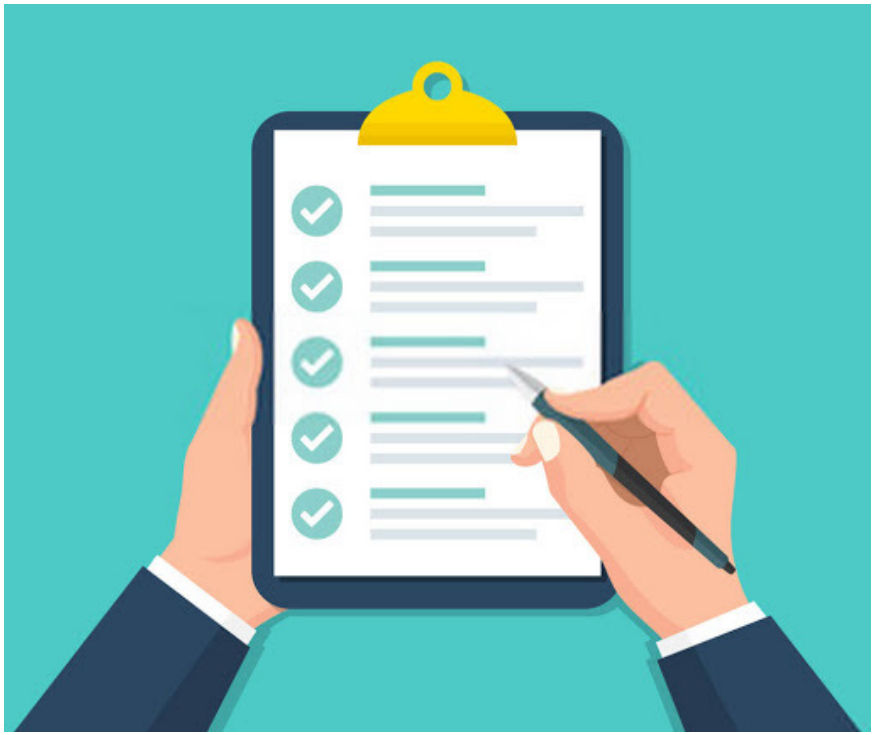
Abbreviation: org, organization. [a]This was the reference group.

In survey research



- Patient trust >> other types of trust
- Trust as independent variable >> Trust as dependent variable

Measures of trust: “Case study” examples



- Physicians’ trust in their patients (Thom)
- Physician trust in organizations (Linzer)
- Patient trust in their clinicians
  - ACES/ PCAS (Safran)
  - Wake Forest Physician Trust Scale (Hall)
- Trust in the medical profession (various)
- Medical mistrust index (LaVeist)

These measures listed as a point of departure,

not an endorsement

Checks and balances based in reality

6-step measurement process	Will measurement…	What will I do with this information?
Who is trusting?	…answer my question?	Is it actionable?
In whom?	Reality check	Do methods match the query?
In what context?		Reality check
Defining trust?		
Self-reflection		
Reality check		

6-step measurement process

1. Who is trusting?	2. In whom?	3. For what?
• Patient • Public • Physician • Clinician	• Patient/ Public • Physician/ Clinician • Organization • System • Profession	• Quality care • Competent care • Improve health outcomes • Good management • Caring

6-step measurement process

4. How would you describe trust in this context?

- Is it more than reliance?

Authenticity
Communication
Confidentiality
Competency
Confidence
Caring
Comfort
Empathy
Equity
Fidelity
Global Trust
Honesty/ Integrity
Logic
Reliability

6-step measurement process

5. Critical self-reflection	6. How much real estate and/or time do you have to give to this?
•Is the process of measurement design inclusive of stakeholder perspectives? Are appropriate voices represented?	•Brief questionnaire on job satisfaction survey? •Anticipating organizational change? •Response to incident?

Will the survey answer my question?

Does the measure I use…	How will I implement the study?
• …evaluate the relationship(s) of interest in the appropriate context? • …assess the elements (i.e., requirements, attributes, principles, or meaning) you decided were important? • …provide useful information to solve a problem or answer your question of interest?	• How will I develop support? • Do I have the time and resources?

What will I do with the information?

1. Is it actionable?	2. Do the methods match?	3. Reality check
• Is the organization (or "audience" prepared? • What is my (or my organization's) commitment to evaluating trust over time? To building or repairing trust?	• Does the survey question(s) I'm using measure what I'm interested in understanding?	• Will a *survey* answer the questions I have about trust in my organization? Am I better off doing interviews, focus groups, or using another method?

Looking ahead

Where do we go from here?

Policy issue

Our digital world will mirror the challenges, biases,
and inequity in our three-dimensional world

Focus on building trust

Large systems can become

too big to care

Trust as a system requirement

- **Familiarity fosters trust**
  (Luhmann, 2000; Meyer S, Ward P, Coveney J, Rogers W., 2008; Giddens 1991)
- **Trust, Mistrust, and Distrust are based on experience**
  (Griffith, 2020; Armstrong (var); LaVeist (var))
- **Trust is relational, and dynamic**
  (Schilke, Reimann, Cook, 2021)
- **Related to risk, uncertainty, power, vulnerability, autonomy**
  (Luhmann, Baier, Giddens, Hall)
- **Meeting (or exceeding) expectations fosters trust**
  (Möllering, 2005; Hsu et al, 2007)

Platt JE, Nong P. Too big to care: An ecosystem approach to earning and sustaining trust in health, JAMA Health Forum (forthcoming)
Taylor L, Nong P, Platt JE. 50 years of Trust Research Milbank Quarterly, (forthcoming)
Zink A, Taylor L, Nong P, Platt JE. Doctors Have to Trust Patients Not to Harm Them Too. Health Affairs Forefront (forthcoming)

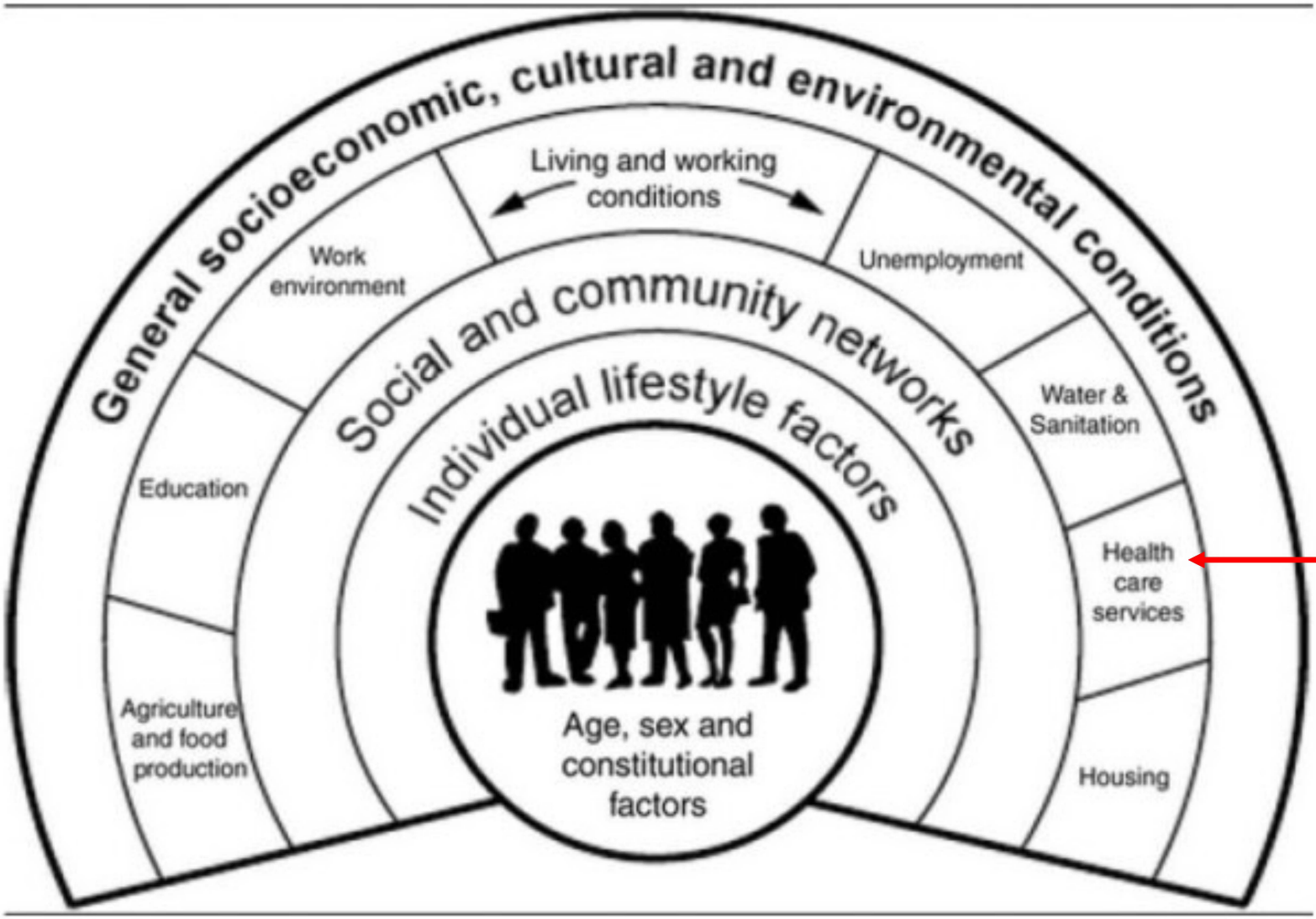
Trusting the public

WORLD VIEW | 12 October 2021

COVID lesson: trust the public with hard truths

When governments assume that people will panic, that exacerbates the pandemic.

Michael Bang Petersen

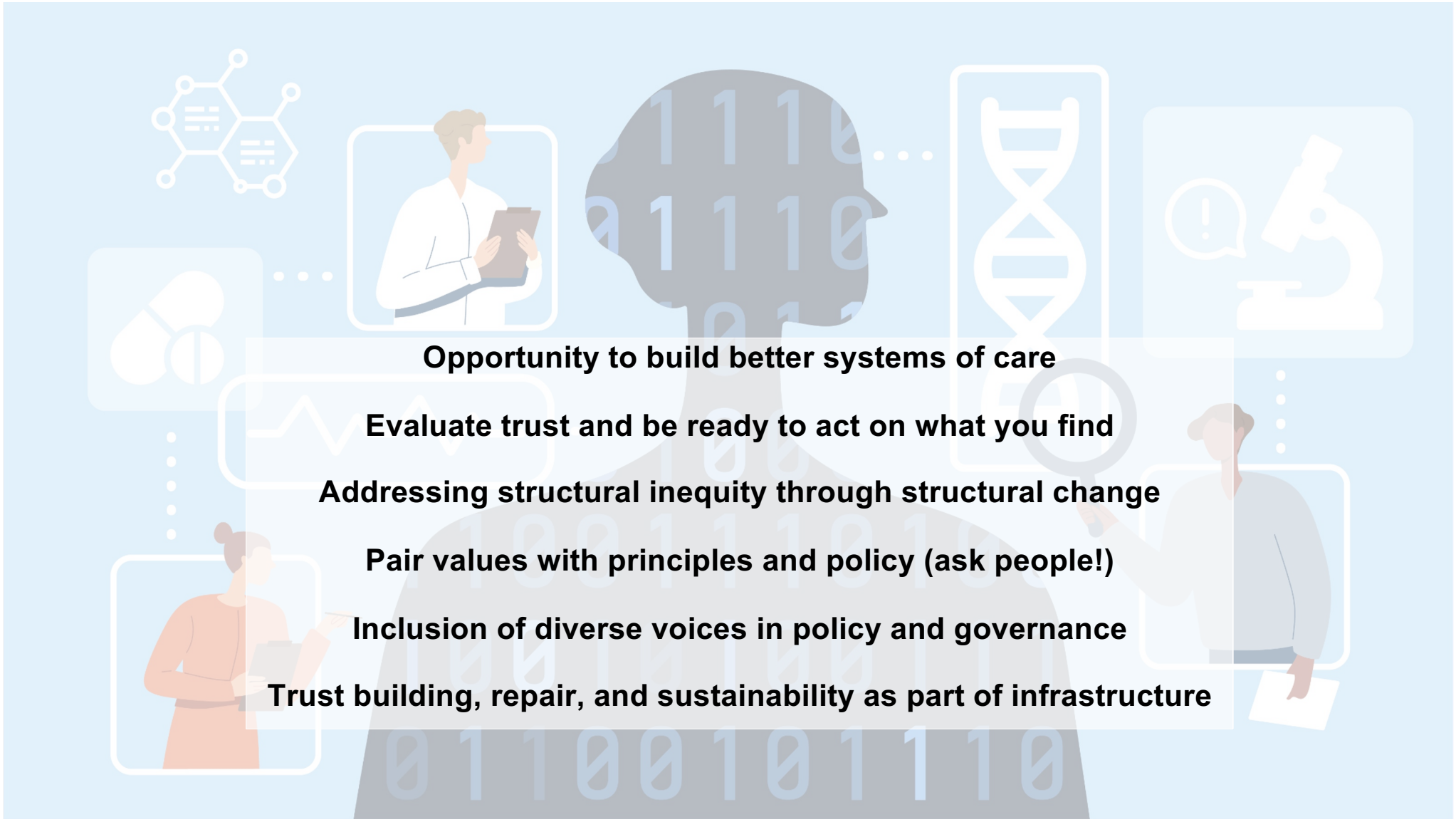

General socioeconomic, cultural and environmental conditions
Living and working conditions
Work environment
Unemployment
Social and community networks
Individual lifestyle factors
Education
Water & Sanitation
Health care services
Agriculture and food production
Housing
Age, sex and constitutional factors

Gratitude as a key value

- Health Services Research
- Informatics
- Public health
- Anti-racism
- Genetics
- Sociology
- Law
- Communications
- Sociotechnical systems

- Ethics
- Design
- Business/ Industry
- Emergency medicine
- Pediatrics
- Nephrology
- Health behavior/ health education
- Community engagement

- Data Science
- Statistics
- Social work
- Precision health
- Anthropology
- Philosophy
- Radiation oncology / Medical Physics
- You!


Opportunity to build better systems of care
Evaluate trust and be ready to act on what you find
Addressing structural inequity through structural change
Pair values with principles and policy (ask people!)
Inclusion of diverse voices in policy and governance
Trust building, repair, and sustainability as part of infrastructure