

Trust in Knowledge Bases and Repositories

Joshua E. Richardson, PhD, MS, MLIS

12/22/2021

Bio, Dr. Joshua Richardson

- Research Health IT Scientist at RTI International
- EHR Implementations, Clinical Decision Support Knowledge Management, Learning Health Systems, mHealth, Chronic Pain and Opioids Management
- Computable evidence from systematic reviews
- Former Assistant Library Director for Clinical Services, Weill Cornell Medicine
- NLM Library Fellow
- MCBK Trust and Policy WG member
- <https://www.linkedin.com/in/jrichardson7/>



Josh Richardson
jrichardson@rti.org

Learning Objectives

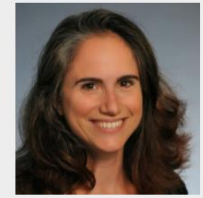
- Describe the MCBK Trust and Policy WG (TPWG)
- Explain how trust and policies relate to CBK
- Describe related research efforts into CBK trust
- Engage in an informed discussion about best practices for trust in CBK

MCBK Trust & Policy Working Group



Blackford Middleton

Co-Chair



Jodyn Platt

Co-Chair

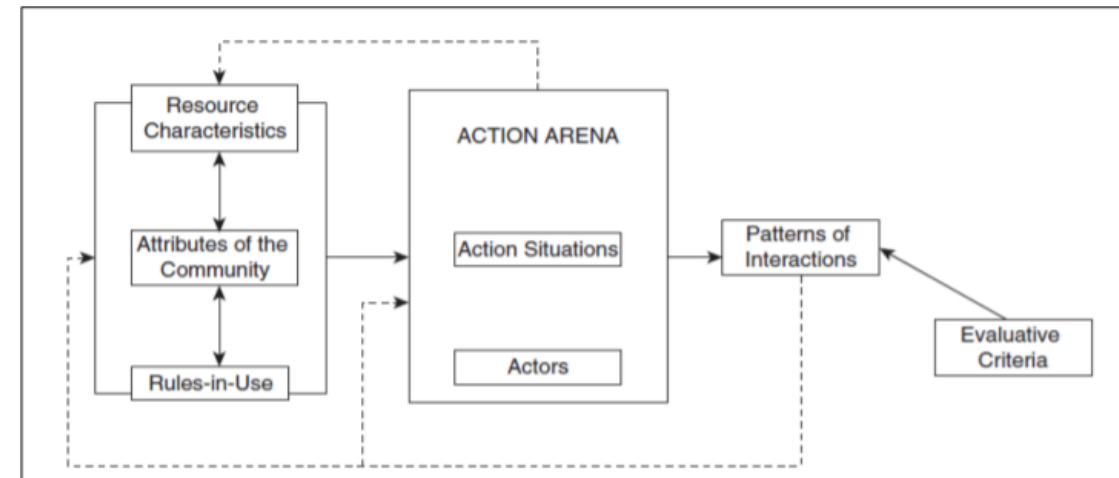
University of Michigan

- Understand the current CBK landscape as it relates to trust, governance of CBK, and policies for CBK.
- Identify roles and opportunities for the MCBK community in promoting transparency and trust.
- Define attributes of and potentially develop prototypes for CBK “product information labels” that would promote transparency of trust.
- Develop model governance structures.
- Develop recommendations for measuring and evaluating trust and transparency of CBK artifacts, implementation, and evaluation.

MCBKPolicyLeads@umich.edu

2019 Poster: Examining the Theories of “Knowledge Commons” and Applications in Learning Health Systems

- Community Attributes: Who are the community members and what are their roles?
- Resource Characteristics: What are the characteristics of the resources?
- Rules in Use: What are the explicit and implicit governance mechanisms, key policies?



Strandburg KJ, Frischmann BM, Madison MJ, editors. Governing Medical Knowledge Commons [Internet]. 1st ed. Cambridge University Press; 2017 [cited 2019 Jul 15]. Available from:

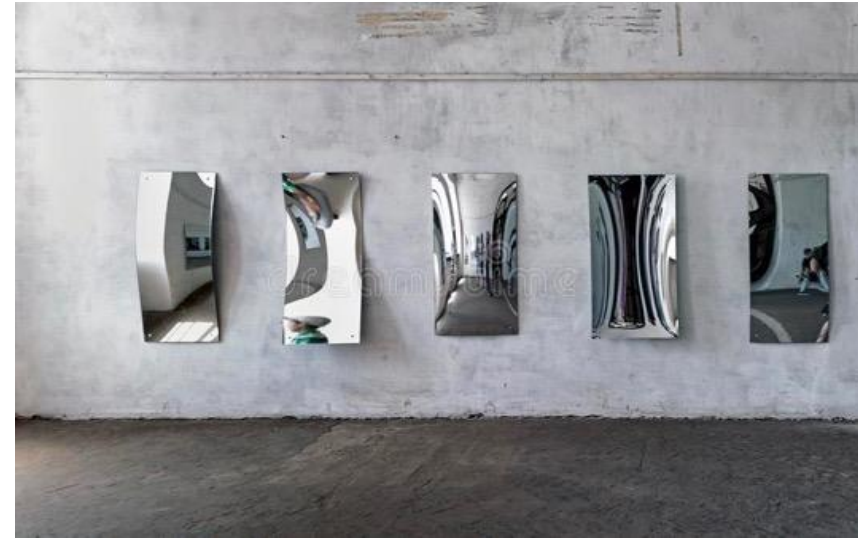
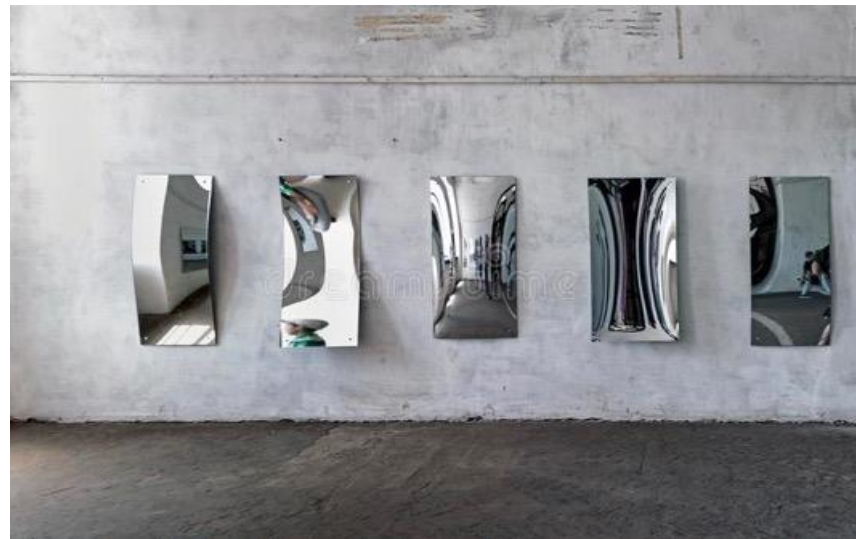
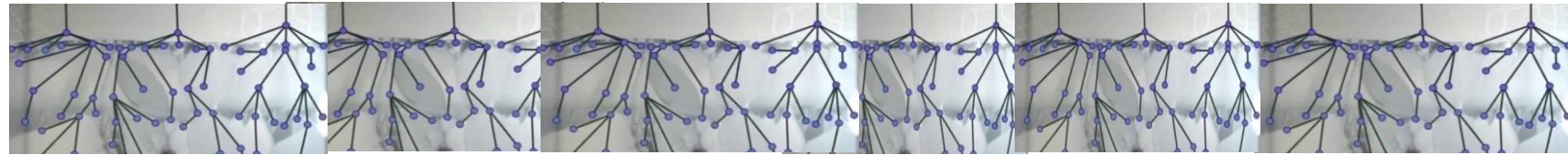
<https://www.cambridge.org/core/product/identifier/9781316544587/type/book>

Why trust?

People and knowledge
are being represented...

...in data, data sets, and
computable knowledge
artifacts.

How do we face the mirrors
of the digital world that
reflect the challenges,
biases, and inequity in our
three-dimensional world?



Why trust so important

- Public trust is an asset that enables “political and clinical autonomy of its practitioners”
- High trust reduces friction (and costs), low trust increases friction (and costs)
- Medicine seen as a public good after decades of work: certification, regulation (internal and external), educational standards, IRBs and ethical commitments
- Threats to trust may include restrictions on patient choices, financial restrictions (e.g. insurance), conflicts of interest, negative news in the media/social media, overall decline in public trust
- Trust is dynamic and fragile, easily damaged due to negative acts or changing contexts, because people attribute more weight to negative events than positive events
- “Trust can be disconfirmed at any time, even after many years.”



“Trust building is an iterative process, requiring repeated evidence of competence, responsibility, and caring.”

Mechanic D, Schlesinger M. The impact of managed care on patients' trust in medical care and their physicians. JAMA. 1996 Jun 5;275(21):1693-7. PMID: 8637148.

What is trust?

- Trust can be understood as “commitment” from another to do something
- Trust is affected by one’s level of knowledge and sincerity to do something
- Knowledge is comprised of skill and expertise
- Sincerity is comprised of intentionality and honesty
- Trust can also built by NOT doing something (when an actor self-admits they lack the requisite knowledge or sincerity)

Types of Trust

Concrete



Generalized

- Interpersonal
 - “I trust *you* to take out the trash when you say you will.”
 - “I trust *you* to make the best medical decision for my best interest.”
- Object
 - “I trust *the car* will start when I turn on the ignition.”
- System
 - “I trust *the insurance company* to cover my medical expenses after co-pay.”
 - “I trust the *hospital* for cardiovascular care but not kidney care because of its US News and World Report Rankings”
- Social
 - “I trust the *institution* to conform to community expectations.”
- Different levels of trust are “correlated and mutually supportive” (Mechanic, 1996)
- Trust in People | Institutions > Trust in Objects

Trust as Emergent Property?

- Arises as social capital and a “feature of social networks” – the stronger the network the greater the capital
- Greater capital can produce greater trust and trustworthiness, and lower transaction costs among network agents (reduces “friction”)
- We may empirically measure trust, trustworthiness, and transaction costs
- Outcomes may include amount of information sharing among types of agents (e.g. buyers vs sellers), speed of information sharing, transaction costs (e.g. negotiated deals, post-contract compliance checking)

See Also: [Jeffrey H. Dyer](#), [Wujin Chu](#). The Role of Trustworthiness in Reducing Transaction Costs and Improving Performance: Empirical Evidence from the United States, Japan, and Korea. *Organization Science* 14 (1) 57-68 <https://doi.org/10.1287/orsc.14.1.57.12806>

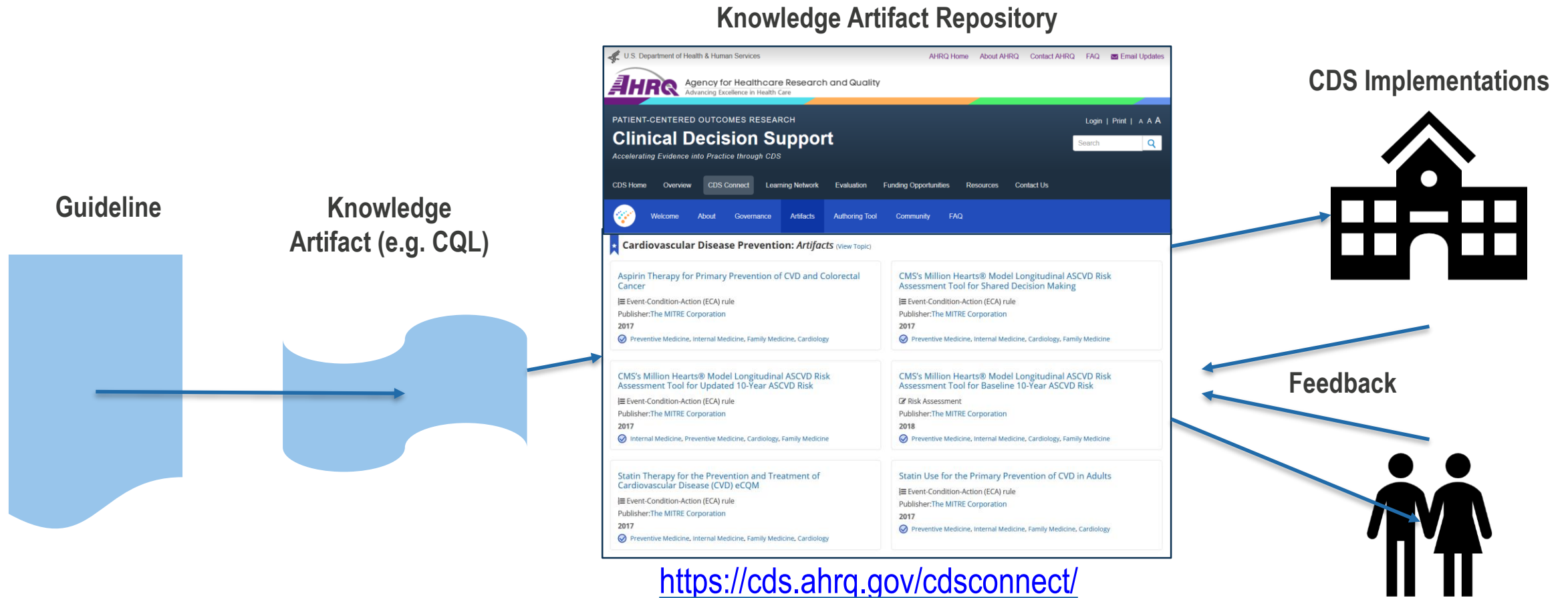
Discuss NY Times Article

- What does the article say are ways that trust/mistrust impact health care?
- What personal examples do you have where trust/mistrust impacted your own care?
- How does your institution convey trust in its information services and products?



Example Research in CBK Trust:
CDS

Shareable clinical decision support provides a new way to disseminate and implement biomedical knowledge

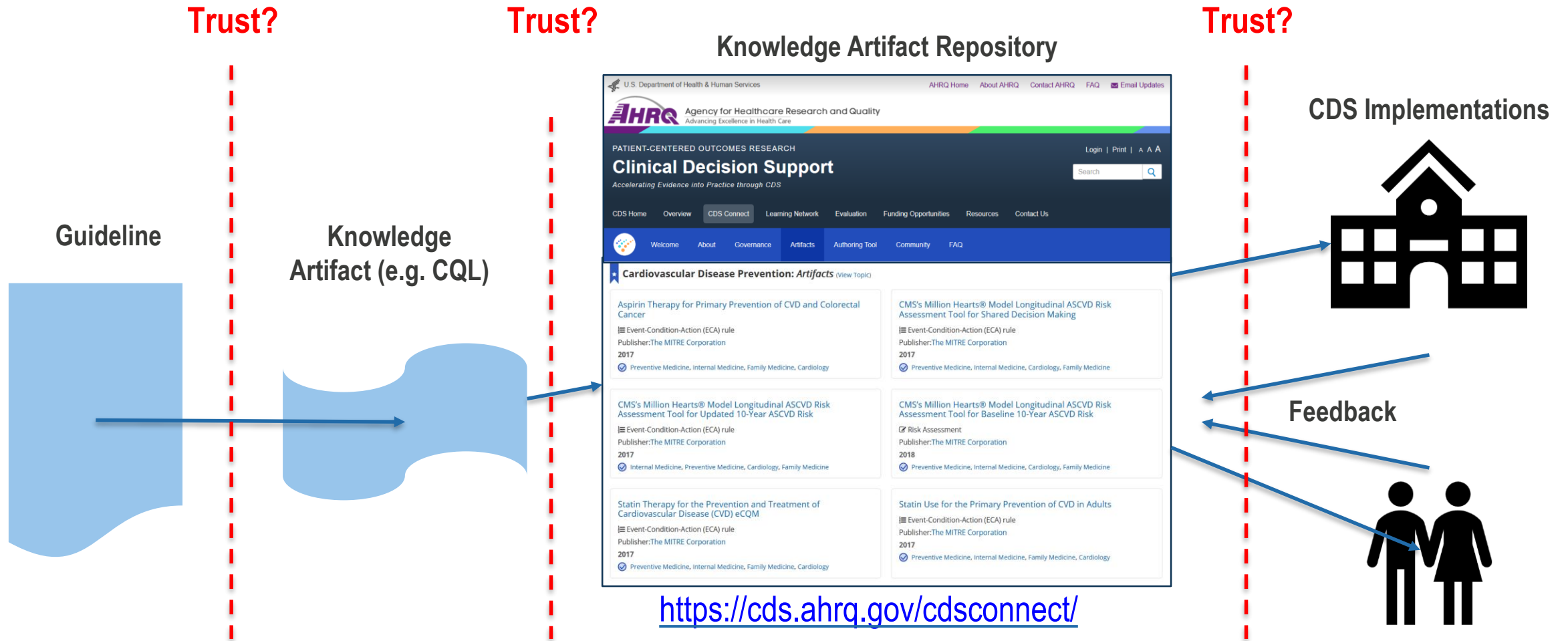


<https://cds.ahrq.gov/cdsconnect/>

11th Annual
Conference on the Science of Dissemination
and Implementation in Health



Shareable clinical decision support provides a new way to disseminate and implement biomedical knowledge



11th Annual
Conference on the Science of Dissemination
and Implementation in Health









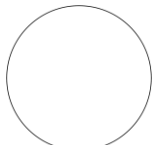
What are the barriers and facilitators to establishing trust that can apply to shareable biomedical knowledge?

- Some barriers
 - Nascent legal frameworks and unclear governance (Hongsermeier et al., 2010)
 - CDS ecosystem involves people with diverse roles and perspectives (Richardson et al., 2010)
 - Technical development of artifacts and platforms
 - Clinical care
 - Patient experience
- Some facilitators
 - Trust is relational and can hinge on contexts of vulnerability or uncertainty (Hall et al, 2002)
 - Ethics of care focuses on relationships (Pols, 2014)

Question: How might trust promote fair, equitable, transparent sharing of knowledge artifacts in a CDS ecosystem?

1	Research	Develop a shared understanding in trust and CDS	<ul style="list-style-type: none">● Presented background webinar (Dr. Platt)● Developed an online bibliography
2	Roles	Define Actors within a CDS ecosystem	<ul style="list-style-type: none">● Conducted group discussions● Surveyed TFWG members● Presented to CDS Connect WG
3	Relationships	Describe relationships between actors	<ul style="list-style-type: none">● Conducted group discussions● Completed matrix exercise
4		Define trust attributes among actors	<ul style="list-style-type: none">● Performed content analyses● Conducted group discussions
5	Recommend	Develop recommendations to address trust attributes	<ul style="list-style-type: none">● Performed content analyses● Surveyed TFWG members● Conducted group discussions
6		Map recommendations to CDS functions (not covered)	<ul style="list-style-type: none">● Conducted group discussions

Attributes of Patient-Centered CDS (Richardson et al)

 Competency	 Compliance	 Consistency
 Discoverability and Accessibility	 Evidence-based	 Feedback and Updating
 Organizational Capacity	 Patient-centeredness	 Transparency



Compliance

A knowledge artifact should conform to defined standards and criteria including copyright and intellectual property.

Compliance recommendations



- Knowledge artifacts provide human-readable and machine-readable forms (whenever applicable) as well as supporting references.
- Knowledge artifacts are implemented in compliance with best-practices for safe and effective implementation.
- Knowledge artifacts are encoded using current standards for controlled medical terminologies, value sets, clinical data models, and knowledge representation formalisms.

We mapped 33 recommendations by trust attribute and archetypal CDS Connect functions

Full Results Available at <https://www.pccds-ln.org/tfwg>

Trust Attribute	Authoring and Uploading CDS Content to CDS Connect	Inspecting and Comparing CDS Content on CDS Connect	Downloading and Using CDS Content on CDS Connect	Providing Feedback on CDS Use in Practice
Evidence-based	<ul style="list-style-type: none">▪ Metadata indicate the date that evidence was originally published, and the date that evidence was last reviewed. (5.1)▪ Metadata state any known limitations, restrictions, or exclusions to any given evidence. (5.2)▪ Artifacts contain references to the evidence base on which they are based, including both narrative guidelines and the data supporting those guidelines. (5.3)▪ Artifacts include metadata for all supporting citations. (5.4)▪ Artifacts include evidence about its method (e.g., order set v. alert), usage history, and available outcomes. (5.5)			

Example Research in CBK Trust:
Public

Preliminary data

(AmeriSpeak Panel, October 2021, n = 150)

How comfortable are you with each type of predictive model?	FDA Classification	Fairly or very comfortable
Models used to <u>diagnose stroke in an emergency</u>	III	66.0%
Models that predict which patients may <u>develop colon cancer</u>	II	59.3%
Models that determine if a patient is <u>eligible for a kidney transplant</u>	II	59.3%
Models that <u>predict which patients might not pay their medical bills</u>	I	25.3%

Preliminary data

(AmeriSpeak Panel, October 2021, n = 150)

	Very or Fairly True
I am comfortable with my provider using predictive models to make decisions about my care	42.7%
If my provider used predictive models in my care, I would expect them <u>to explain what the predictions mean</u>	95.3%
If my provider used predictive models in my care, I would expect them to <u>understand how the models work</u>	95.3%

Preliminary data

- More coming!
- AmeriSpeak Panel, November 2021
- $n = \sim 1600$

- Portal use
- Health care access
- Trust in the health system
- Trust in providers
- Caregiving
- Experiences of discrimination
- Attitudes about health information sharing

Example Research in CBK Trust: Knowledge Repositories

MCBK TPWG Survey (Under Review)

- An online survey to assess the current policies and practices governing these repositories and to identify best practices
- 13 responding organizations
- All organizations surveyed to different degrees adhere to policies that convey TRUST
- Few organizations publicly describe whether patients play any role in their decision-making
- Identifying current practices suggests a set of desiderata for the CBK ecosystem to pursue in its continued evolution

Lin et al.'s TRUST Principles

Principle	Definition
Transparency	To be transparent about specific repository services and data holdings that are verifiable by publicly accessible evidence.
Responsibility	To be responsible for ensuring the authenticity and integrity of data holdings and for the reliability and persistence of its service.
User Focus	To ensure that the data management norms and expectations of target user communities are met.
Sustainability	To sustain services and preserve data holdings for the long-term.
Technology	To provide infrastructure and capabilities to support secure, persistent, and reliable services.

Examples of Transparency

TRUST Principal	Common Practices (n) [>= 7]	Moderately Common Practices (n) [3-6]	Uncommon Practices (n) [<= 2]
Transparency	<ul style="list-style-type: none"> • Policies for conveying provenance (n=11) • Policies for credentialed contributors (n=8) • Metadata is associated with - date the knowledge product was originally published (n=12) • Metadata is associated with - last reviewed (n=9) • Metadata is associated with - references to the evidence base(s) (n=11) • Metadata is associated with - Citation(s) (n=11) • Posted Procedures describe - implementing, updating, revising, or de-implementing knowledge products (n=7) 	<ul style="list-style-type: none"> • Metadata is associated with - known limitations, restrictions, or exclusions to any given evidence (n=6) • Posted Procedures describe - Posted Procedures describe conflict of interest (n=5) • Posted procedures describe licensing agreements or secondary use rights (n=6) 	<ul style="list-style-type: none"> • Metadata is associated with - user history (n=2) • Metadata is associated with - feedback (n=2)

Examples of Sustainability

TRUST Principal	Common Practices (n) [>= 7]	Moderately Common Practices (n) [3-6]	Uncommon Practices (n) [<= 2]
Sustainability	<ul style="list-style-type: none"> Require user attribution of artifacts used in future products (n=8) 	<ul style="list-style-type: none"> Post a description of its governance structure (n=5) Quality control policies or procedures in place (ensure the correctness or accuracy of artifacts) (n=6) Sustainability plan in place (n=6) 	<ul style="list-style-type: none"> Patients included in governance decision making (n=2)

Proposed Desiderata: Transparency

Domain	Best Practice
Transparency	<ul style="list-style-type: none">• Policies for conveying provenance• Policies for credentialed contributors• Knowledge Management meta-data (sources/citations, publication date, updates, revision cycle)• Implementation and Use Guidance• CBK Metadata to describe - known limitations, restrictions, or exclusions to use any CBK• Declarations by all authors and sources of potential conflict of interest• CBK with stated procedures describing licensing agreements or secondary use rights (if any)• CBK with standard preferred citation formats• CBK designed and implemented for use with standard clinical data models• CBK end-user comments are accessible, searchable• CBK that is certified by an external agency to the CBK repository and deemed safe and effective for use

Proposed Desiderata

Domain	Best Practice
Responsibility	<ul style="list-style-type: none">• CBK Stored in current standard(s) machine readable format• CBK encoded with current terminology standards, value sets, expressions• CBK encoded with current standard knowledge representation formalism(s)• CBK products are developed in compliance with best practices for knowledge engineering

Proposed Desiderata

Domain	Best Practice
User-Focus	<ul style="list-style-type: none">• CBK Repositories promote end user-feedback, and visibility on other CBK artifact implementations• CBK updated based on user-provided feedback• CBK user with clear end user licensing agreement (free, or paid)• CBK EULA clearly states the rights and responsibilities of the author or publisher of CBK• CBK enhances health outcomes and improves health equity

Proposed Desiderata

Domain	Best Practice
Sustainability	<ul style="list-style-type: none">• CBK conveys attribution of artifacts• CBK Repository clearly states governance structure• CBK Repositories include patient and public advocates in governance structure• CBK development includes appropriate quality control / quality assurance procedures to assure appropriate, safe, and effective use• CBK Repository has sustainability plan in place (both public and private repositories)

Proposed Desiderata

Domain	Best Practice
Technology	<ul style="list-style-type: none">• CBK Repository supports version control• CBK is FAIR – findable, accessible, interoperable, and reusable• CBK meta-data to track updates and changes over time• CBK Repositories offer an API to access or use CBK (run-time)

Discussion Questions

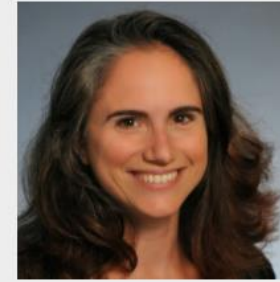
- What proposed best practice(s) do you most strongly agree with?
- What proposed best practice(s) do you most strongly disagree with?
- What best practice(s) are missing?

MCBK TPWG



Blackford Middleton

Co-Chair



Jody Platt

Co-Chair

University of Michigan

- Understand the current CBK landscape as it relates to trust, governance of CBK, and policies for CBK.
- Identify roles and opportunities for the MCBK community in promoting transparency and trust.
- Define attributes of and potentially develop prototypes for CBK “product information labels” that would promote transparency of trust.
- Develop model governance structures.
- Develop recommendations for measuring and evaluating trust and transparency of CBK artifacts, implementation, and evaluation.

MCBKPolicyLeads@umich.edu



Thank you

Joshua E. Richardson

jrichardson@rti.org