Mobilizing Computable
Biomedical Knowledge

Briefing paper on:

Establishing a Trusted System for Computable Biomedical Knowledge (CBK)

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What is trust?

DEFINITION OF TRUST

Trust is the willingness to be vulnerable to another in the fulfillment of a task. Trust is important because it provides opportunities for greater efficiency in managing and sharing health information and knowledge, which, in turn, may translate into greater satisfaction and confidence in the health system.[1]

TRUST IN ACTION: BANKING

Banking exemplifies the value and importance of trust: a customer invests her money with a bank for safe-keeping; the bank can then use that money for any number of larger investments that benefit the bank, translating the investments of customers into the convenience of debit cards, online banking, and the accrual of interest. The customer likely does not understand the rules and regulations governing the bank, nor does she need to. And yet the customer's confidence in the banking system to take good care of one's money (and return it when asked) is critical to the banking system's functioning and operability.

KEY PARAMETERS OF TRUST

Trust has 4 key parameters: (1) Someone who trusts (trustor); (2) Structure of trust; (3) Object of trust (trustee); and (4) a task, contingency, and/or boundary. For example: Dr. Episteme trusts Dr. Phronesis to create an instance of CBK from her work. In this example, Dr. Episteme is the trustor (1); Dr. Phronesis is the object of trust (3). The creation of CBK from Dr. Episteme's work is the task (4). The task is shaped by context such as rules, culture, and resources that impact Dr. Prhonesis' capacity to create CBK. The structure of trust (2) is described below.

Thought Question:

Who are the trustors, the objects of trust, and the tasks in the context of CBK? i.e., Who trusts whom (or what) to do what, and under what conditions?

Trust is a Multi-faceted Concept

Nearly all forms of trust are relational, even when object is an abstract "system," an inanimate object, institution, or structure. Individuals may represent systems when, for example, a physician represents the entire health system to the patient or when a CIO chooses to trust one CBK system over another because of the quality of the work and the product. The more "human" a system, the greater the opportunity to build and sustain trust.[2] In 2012, Susan Gubar, wrote a memoir recounting her experience with a series of medical errors in surgeries she had to treat ovarian cancer, and noted that a system that is an "anonymous smokescreen" is less trustworthy than one that achieves human accomplishments and makes human errors. [3]

Trust can be *generalized*, i.e., based on intuition or perception, or *specific*, based on an ongoing relationship. For example, a physician with a patient she doesn't know very well may base trust on "more a gut feeling" (generalized trust), while "with colleagues [whom she knows very well], it's more of a cognitive process" (specific trust).[2]

Two related concepts that are helpful in discussing trust are *distrust* and *trustworthiness*. *Distrust* is skepticism or lack of willingness to engage with another because you expect failure. Notably, trust in health and health care has been declining for the past several decades. *Trustworthiness* describes the trustee in a relationship and is necessary but not sufficient in a trusted system.[4]

Structure of trust

Trust is a complex concept and clearly a value in health, systems, and for CBK. Understanding the underlying structure for a given context allows us to identify key principles and better describe the "trust fabric." The structure of trust can be described in terms of several properties:[5]

- ❑ Competency
- ❑ Integrity
- ❑ Fidelity
- ❑ Security
- ❑ Safety
- ❑ Genuineness
- ❑ Reliability

- ❑ Dependability
- ❑ Honor
- ❑ Relationship
- ❑ Accountability
- ❑ Generosity
- ❑ Motivation

Question: Which properties of trust are most relevant to CBK and the relationships identified above?

Trust Demonstrations: Building and breaking trust

It is broadly recognized that trust is easier to break than to build it. Further, maintaining and building trust both require active attention. Effective communication, transparency, time, and active demonstration of trustworthiness are key to building and sustaining trust. While these may seem like grand gestures, acts of building trust are often small, personal acts. Each act is a demonstration of the properties listed above and forms a basis of trust or distrust. For example, the process of informed consent is frequently cited as a trust building exchange that shows integrity, honor, and communicates accountability of a researcher or clinician to a research participant or patient. An example of *trust being violated* is the case of newborn screening bloodpsots being used to help the military build a DNA database in the state of Texas. Here, the integrity, fidelity, and motivation of the health department was called into question; ultimately, in this case, the bloodspot cards were destroyed, suggesting the dire consequences of a loss of trust. In hindsight, a better evaluation of the nature and properties of trust, and of its quality might have led the newborn screening program down an alternate path.

Question: How are the properties of trust in CBK systems demonstrated?

Examples of trusted systems relevant to CBK

Digital Libraries

JSTOR, an academic digital library, (www.jstor.org) was first established in 1996 as an independent nonprofit, after a pilot launched by University of Michigan. As a resource for researchers and academics, JSTOR's founding at a major research institution, provided it with an early legitimacy. More than 10 years later, JSTOR merged with and became a service of another nonprofit, ITHAKA. The not-for-profit structure of ITHAKA and JSTOR, along with the well-respected academics and librarians who make up their trustees and advisory boards, help perpetuate user trust. JSTOR currently works with librarians and publishers to offer more than 10 million academic journal articles, as well as numerous books and primary source documents to scholars around the world.

Relationships: researchers, academics, JSTOR, digital publications; UM, ITHAKA
Structure: Integrity, reliability, security
Demonstrations: Non-profit structure; public/ accessible governance

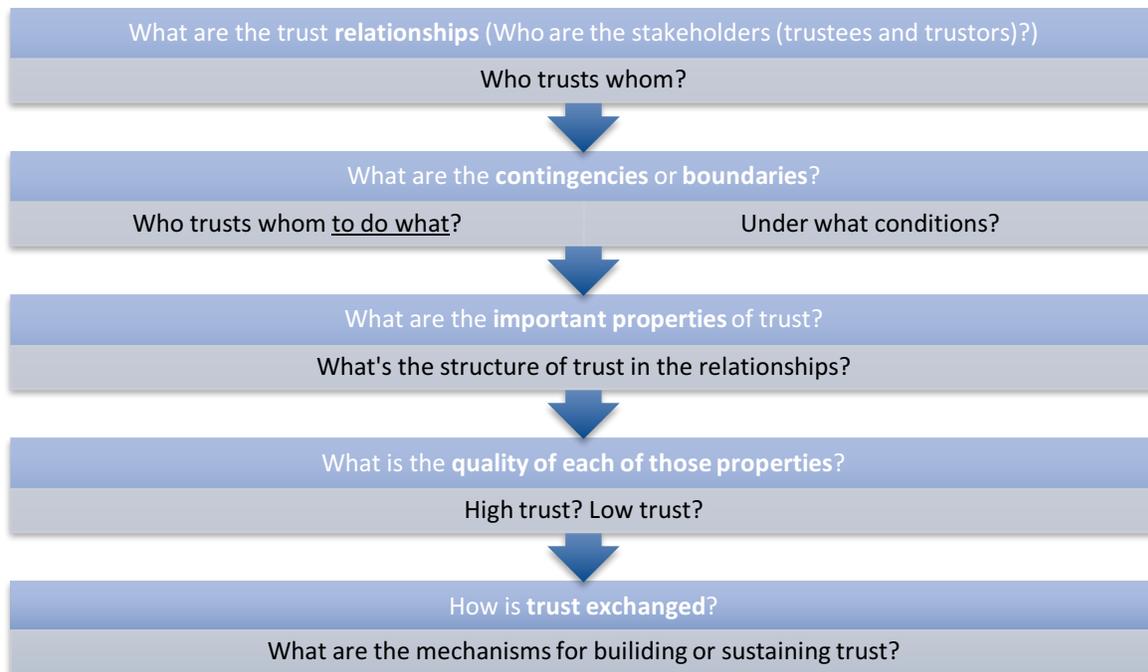**Population health screening: Newborn screening**

Criteria for determining whether a disease should be screened for at the population level still relies heavily on principles developed in the late 1960's, particularly in the context of newborn screening. Wilson and Jungner[6] articulated 10 criteria for population screening (See box below) that provide accountability for decision-making and guidance for policy makers. Programs, such as newborn screening, that adopt these criteria use them to demonstrate trustworthiness and to be able to articulate rationale for decision making.

Relationships: The public (patients, families), public health institutions, knowledge, medical professionals, technology

Structure: Competency, reliability, security, fidelity

Demonstrations: Test sensitivity and specificity, communication, policy

TRUST FRAMEWORK

What are the trust **relationships** (Who are the stakeholders (trustees and trustors)?)

Who trusts whom?

What are the **contingencies** or **boundaries**?

Who trusts whom to do what?   Under what conditions?

What are the **important properties** of trust?

What's the structure of trust in the relationships?

What is the **quality of each of those properties**?

High trust? Low trust?

How is **trust exchanged**?

What are the mechanisms for builiding or sustaining trust?

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