Challenges of the TEFCA Scatter Model show the Vital Need to Establish the Individual at the Center

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TEFCA

- US Office of National Coordinator's Proposed Trusted Exchange Framework Common Agreement
- TEFCA is proposed to bridge multiple health information networks (HINs) and connected systems/devices: the Scatter Model
- TEFCA relies on real-time queries to discover and retrieve patient health records

TEFCA Scatter Model – The Problem

Magnitude

- 10s and 100s of health information networks (HINs)
- 1000s, 10000s (and beyond) systems/devices
  - Electronic health records (EHRs), Personal health records (PHRs)
  - Hospitals, clinics, emergent/urgent care, long-term care...
  - Behavioral health...
  - Military, Veterans Administration, Indian Health...
  - Clinical labs, pharmacies, imaging facilities...
  - Public health...
  - Schools, daycare...
  - Payers, health plans, Medicare, Medicaid...
  - Devices, wearables...

TEFCA Scatter Model – The Problem

Query the Universe – Every Time

- Only a small fraction of these systems/devices contain any health record(s) for an individual (patient), indeed:
  - A fragment here, another fragment there
- Record locations are often unknown to querying persons/systems
- Record fragments may be decades old and/or entirely irrelevant
- Institutions where care occurred may no longer exist

→ All possible systems/devices must be queried each time

TEFCA Scatter Model – The Problem

Lack of Continuous Monitoring/Guidance

- Individual health and healthcare
  - Should be (able to be) supported continuously – without interruption or gaps
  - Enabled by real-time monitoring and guidance
  - Even when ‘no one is looking’
- There is no provision for – and no system available/working 24 x 7 – in the space between institutions – where individuals spend their entire lives

Challenges of the TEFCA Scatter Model

Confidentiality, Minimum Necessary

Ensuring record content is held confidential and otherwise constrained to that which is the “minimum necessary”

- Based on:
  - User
  - Intended use: treatment, payment, operations, public health, research/clinical trials, marketing...
- Is it determined by (likely varying) rules of one or more:
  - Querying institution/system?
  - HINs?
  - Queried institutions/systems/devices?

→ Records returned are those conjured to satisfy one query only

Challenges of the TEFCA Scatter Model

Authorization, Consent

Ensuring access to record content is constrained to that which is authorized and/or consented

- Based on:
  - User
  - Intended use: treatment, payment, operations, public health, research/clinical trials, marketing...
- Is it determined by (likely varying) rules of one or more:
  - Querying institution/system?
  - HINs?
  - Queried institutions/systems/devices?

→ Records returned are those conjured to satisfy one query only

Challenges of the TEFCA Scatter Model

Response or Not

At time of query, there may be:

- No response, network and/or system is:
  - On-line
  - Off-line
- No record(s) found, none returned
- Record(s) found, but none (or no indication) returned:
  - Deemed sensitive: e.g., HIV, alcohol/drug, behavioral
  - Not deemed authorized and/or consented
- Record(s) found and returned

→ Record(s) returned are those conjured to satisfy one query only

Challenges of the TEFCA Scatter Model

Response = Nada, Trickle, Deluge

- Record entries returned from single query:
  - None
  - Few (<= 10)
  - Moderate (<= 100)
  - Many (> 100)
  - Massive (> 1000)
- Record entry, e.g.,
  - One order, one diagnostic result, one medication, one treatment, one assessment or progress note...
- Querying system/person (typically) has no idea what to expect

→ You don't know what you don't know

Challenges of the TEFCA Scatter Model

Response Delay Factor

- A minute waiting is a minute wasted
- Querying system/user typically doesn't know what to expect (how long the delay will be)
- Delay factor (query to response time) is unknown

→ You don't know what you don't know

Delay	As in...	Actionable?
Seconds	<= 60 sec	In real-time?
Minutes	<= 60 min	?
Hours	<= 24 hrs	?
Days	<= 30 days	?

Challenges of the TEFCA Scatter Model

Response Variance, Completeness

- Consider potential variance (as described previously):
  - Confidentiality, minimum necessary
  - Authorization, consent
  - Response (or not), response volumes, response delay factors
- Identical queries posted at different times, or even in immediate succession, may produce different results
- It is never possible for the querying system/person to determine if the sum of responses (to a query) have yielded a complete, or mostly incomplete, record thus

→ You don't know what you don't know

Challenges of the TEFCA Scatter Model

Pertinence, Timeliness, Actionability

- Actionable in context of intended use
  - E.g., for primary use: clinical care, interventions, decision making
- Health Record Content is either:
  - Pertinent and timely, thus actionable
  - Not pertinent, irrelevant and/or stale/expired, thus not actionable
- Actionability is:
  - (Typically) determined by a human after record(s) received, and
  - After en masse review

→ Record(s) returned may be pertinent, timely and actionable (or not)

Challenges of the TEFCA Scatter Model

Transaction Load and Scale

- Based on the TEFCA architecture, all systems/devices must be included in every query
- What might be the query processing load on each?
  - Transactions per day: 100s, 1000s, 10000s, more?
- How many systems/devices are added/removed each day?
  - 100s, 1000s?

→ How might this scale over time? US and international?

The TEFCA Conundrum

Despite the Stated Objective...

- “The vision we seek to achieve is a system where individuals are at the center of their care and where providers have the ability to securely access and use health information from different sources. A system where an individual’s health information is not limited to what is stored in electronic health records (EHRs), but includes information from many different sources (including technologies that individuals use every day) and provides a longitudinal picture of their health.” – Draft TEFCA Introduction, 5 January 2018

The TEFCA Conundrum

The Vanishing Individual

- TEFCA aspires to each individual being at the center of their own care and yet in information terms there is nowhere to point to that is that center.
- Individuals remain as passive parameters in the workings of institutional systems and the exchanges between them.
- An individual has no independent existence. He/she remains scattered and fragmented across institutions, HINs, systems and devices.
- We speak of an individual's health information as if this is a coherent entity we use and contribute to. But it is not. At best it is a notion to be found either somewhere, everywhere, or nowhere.
- This is no basis for informed individual-centered health care.

The TEFCA Conundrum

Misalignment

- The obsession with the difficulties of data exchange standards distracts from the underlying architectural misalignment between information processes and individual health care itself.
- TEFCA proposes a HIN of HINs. The very need for such an overarching agreement is a reflection of the impossible many-to-many complexities of direct inter-institutional arrangements.
- The answer to tackling the complexity is not more of the same. The workings of institutions can no longer act as proxies for the experiences of an individual. The perspective on the problem needs reorienting:
  - There is no need for institutions to interoperate directly with each other for purposes beyond immediate business relationships.
  - There is a need to provide care to an individual patient that fits with that individual's overall health and healthcare.

The Solution

A Center for the Individual

- This fundamental conceptual misalignment leads to two category errors:
  i. Trying to solve a problem that does not need solving and is intractable
     - As evidenced by the TEFCA Scatter Model; and
  ii. Failing to solve the one that does need solving and is tractable
     - Establishing the individual at the center.

A Center for the Individual

Making It Real

- No amount of information standards will answer these “Scatter Model” questions.
- The problem that needs solving is making the 'center' real: by creating the system that ‘serves the individual’.
  - Institutions then interact with that system as a routine part of care and as part of the duty of care, contributing to a persistent coherent record of an individual's overall health and care.
  - Institutions make use of that record when needed without recourse to interactions with other institutions.
  - Institutions continue to operate their own systems for their own purposes, recording a lot of the operational details of the care they provided.

A Center for the Individual

Joining the Carer and the Cared For

- The aim is to ensure individuals get coherent, “joined-up” care.
- This can only be achieved if the individual is the conceptual design center of our information infrastructure.
- Care is provided to individuals and hence information should align with that care.
- Exchanges should be between the individual and those providing them with care.

→ Institutions need to stop talking *about* individuals and talk *with* them.

A Center for the Individual

~~Many to Many~~ One to Many

- Pursuit of HIEs and the belief the obstacle (alone) is standards will continue to distract from the
  - Fundamental need to architect a new individual-centered infrastructure that is distinct from, but works with, the existing institutional systems.
- With the proper architecture, the
  - Many-to-many problems created by HIEs can be transformed into a
  - One-to-many architecture with the one being the individual at the center.

Intractable vs. Tractable

Scattered vs. Centered

	TEFCA Scatter Model	**At the Center – Individual Health Record (IHR)**
Basics	Patient data/records are managed across 10s and 100s of HINs and 1000s of systems/ devices, each of which maintains/manages: • Trusted software and storage • Accountability, authentication, authorization, consents, access control, audit mechanisms • Some fragment of the patient record	A designated and secure system which is: • Patient-controlled and provider neutral • Maintained by a trusted custodian organization Where the patient or their representative: • Maintains an electronic account and address • Maintains/designates a single place to send/ store their records, e.g., after each encounter
Broadcast query	Query goes to 10s or 100s of HINs, then on to 1000s or 10000s of systems/devices	Query is directed to a single designated IHR custodian and account for each patient
Query response	• Response may be nothing, trickle or deluge • Response content may vary each time • Response may be minutes, hours or days • You don't know what you don't know • You don't know how long to wait	• Response is immediate • All relevant and permitted records are immediately available • You immediately know what you need to know
Confidentiality/ Authorization	Managed within a complex lattice of provider and HIN permissions plus patient consents	Managed at a single point by each patient and/or patient representative
Real-time + Continuous	[Not Applicable]	Sustained (24 x 7) support for individual health and healthcare – monitoring and guidance

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