Inceptary 15
Misinformation and Health Directives

Last sessions' follow-ups

Our last two sessions revolved around vaccine hesitancy, first from an effort to understand, and second how to facilitate discourse among people with varying beliefs that improves understanding and does not end in a no-win situation with people dogmatically defending their own tribe's popular convictions. This latter subject we continued in this session.

New ideas, initiatives

The Bottom-Up Health Directive

Triggered by the New York Times article on the use of public cameras to track seniors, we identified an opportunity to design and prototype a new type of Advanced Health Care Directive (AHCD).

Where a Thousand Digital Eyes Keep Watch Over the Elderly
tinyurl.com/yy8netz6

Encouraged by at least two in our session, we moved right into the broader discussion of how to communicate our care desires while we can still decide, to those who may need to approve health services, (EMTs, ERs, MD, Hospitals), and to those who would represent us (family and our predetermined proxies).

We aim to address these challenges that today, despite having an AHCD, in most cases still exist:

- Is this the latest copy? My latest wish?
- Where is it? (e.g., providing it to EMTs and ERs, at home? or what if we are travelling?)
- There isn't much privacy in a paper document.
- There are disconnected islands of e-AHCD (usually centrally controlled databases)
- AHCDs today do not address emerging use of monitoring technologies to prolong living independently – for example: cameras, chips, biometric and emotional sensors.

We discussed distributed ledgers (sometime called blockchains) as a possible, relatively easy to build prototype for a solution that would address all of the above challenges Control would reside in the hands of the individual, as opposed to government, business, or any other organization. With a distributed ledger approach the information would always be:

- up to date, directly managed by the individual wherever they choose to keep the data,
- private (encrypted with access control) using "smart contracts" that identify who can access what portion of the data.
- virtually impossible to hack.

We will explore a solution that preserves the latest wishes, with personal independence and a commitment to distributed control. By using an existing platform like Ethereum, it should be possible with a small investment to develop a working prototype.

Areas of analysis required:

- Competitive solutions in the market
- Explore any legal acceptance challenges
- Explore access protocols and technologies, and information accessibility by individual groups of users: EMTs, Medical services, families, proxies, others?

Tasks toward funding a prototype:

1. Architect a solution
2. Budget a development project
3. Secure grant/funding for development, market analysis, feasibility and acceptability tests.

Any volunteers to explore this further?

<u>Literacy, in its broadest sense</u>

Not a project per se, but perhaps an outcome that is simply "5 Things to Do When You Encounter Different Beliefs."

During Covid we all struggled with the impact of different types of mandates, unvaccinated individuals overloading hospitals, limited services to those with other acute heath emergencies. We struggled with the language, the assumptions, the narrow beliefs almost cleanly divided by politics. Expressions of anger, blaming the sheeple or the stupid, misinterpretations and willful misrepresentations by those in power, grasping at answers from unique, small, or falsified data, and by those who amplified it. We became more divided by the common real injury to livelihood, social connection, and those in most business environments, while trust in government, public health, science, business, religious groups became suspect, if not destroyed.

While "The 5 Things to Do…" may still be elusive, we did adopt two concepts as possible paths. Both rooted in illiteracy (lack of understanding). The first we'll call our own illiteracy of others' needs and goals, the second is media literacy.

These approaches are based on the objective that to get tangible results blaming or shaming people does not work. Implying that for some reason they are susceptible to disinformation does not work either, since this makes them defensive. We believe that the best approach is to provide a menu of options to people with guardrails and scaffolding that will help them seek qualified advice.

The first is based on a process that several of us, as management consultants use to settle deep, personally-invested, business management "religious wars," from relatively less important decisions like - which IT system to purchase, to consequential priorities on which initiatives to fund.

The concept requires acknowledgement of your illiteracy about other person(s) goals. You cannot know what they want, and why they want it – until they express it; the need to acknowledge that whatever they believe is in fact what they believe, regardless of what you think is right. For example, one failure of liberals is that they persistently think they know what people need.

The approach is to keep backing up to an ever-broader goal until there can be an aligned view. For example – refusal to get a vaccine is indeed a goal, but can you align at a higher level? Is it to not get Covid, to not be ill from Covid, to not die from Covid, to not leave your children orphans? Where can alignment be found?

It is highly likely that the majority of the population would agree that they would rather not contract Covid-19, and if they do contract Covid-19, that they recover as quickly as possible and do not have any long-term ill health (long Covid).

If so, then there is a menu of choices that we would do for any other infectious disease. Now this is where the second approach would come into play – that of media literacy, and here specifically health literacy.

This brings us back to our very first Inceptary session in 2019 where our proposed hypothesis was "the reason healthcare in the US in so much trouble is that the general population does not understand basic health knowledge." That discussion brought us the Reimagining Rural Health initiative. We now re-engage that conversation in light of an overlay (a barrier?) of misinformation. We'll broaden the discussion to media literacy as a vehicle for cutting through misinformation. The following interesting articles illustrate media literacy – with a little focus on Finland who have over the evolved a way to defend against misinformation.

The 2021 Media Literacy Index touches on Covid
https://osis.bg/?p=3750&lang=en

Finland's leading efforts in education
https://www.theguardian.com/world/2020/jan/28/fact-from-fiction-finlands-new-lessons-in-combating-fake-news

California's proposed regulatory (as opposed to educational) approach may well stifle innovation
https://www.sfgate.com/politics-op-eds/article/argument-against-California-AB-2098-17130301.php

An interesting take on health misinformation (health literacy) from FDA chief – no data though
https://www.cnn.com/videos/health/2022/05/07/fda-robert-califf-intv-misinformation-death-sot-vpx.cnn

Existing initiatives updates

Reimagining Rural Health

Our investigation of work in eastern Indiana has been delayed again, our sponsor on medical leave until the end of June.

As an alternative modeled on Indiana, after a careful review of California counties, we are preparing a project proposal for Kern County as a stand-in for a rural California county. Kern County tends to rank near the bottom of California counties in both health behaviors and health outcomes.

EHR 3.0

The time limit to deliver to the NSF a full grant application has passed. Our project was complex, ambitious, too ambitious for the time we had to pursue it. As with all our ideas and project designs, EHR 3.0 is available for anyone to pursue.

Post-Acute

Several members have put in a good deal of work to create a research questionnaire for those who have gone through a discharge process to gather their experiences and needs in hindsight. The questionnaire is available on Slack for discussion and comments. We'll discuss the questionnaire and how to deploy it at our June session.

Ideas previously raised to keep in mind

Caregiver issues – burnout, stress, burden of family members caring for family members. Particularly aging and especially dementia. Seeing more and more need, and lacking solutions.

Care staff crisis – during covid many have gone on to different careers. Senior care is not an interesting career path today.

- How do we manage care with fewer care staff, fewer nurses?
- How can we deliver on proper protocol with informal care givers?
- Access to what knowledge is needed to create a viable solution to this global problem?
- Is there a role for digital, remote data collection that can guide short-term actions in support of chromic care?

Write a 2030 healthcare white paper

- Bring tactical scenarios we are experiencing in the field and bring them to the team
- Shortage of nursing and care staff – can that be addressed by tech – to increase "productivity"
- Using the broader population of nursing, professional and informal care staff to deliver "close-to" MD office visits remotely.

Can we use technology more effectively at Inceptary?

- Initiate and promote Slack usage by topic channels, reference information and group interaction beyond our sessions.