Sept 14th CHDC Working Group Meeting Notes | Takeaways:

- The last several months have featured numerous conversations with the Working Group stakeholders, each being leaders of one of the three"legs" of Connecticut's healthcare industry, representing providers of healthcare services, insurance companies, and researchers (in academia or as entrepreneurs). Technology and IT advances have the potential to balance them and bind them together. Each of these groups is here represented by champions in their field, all of whom are involved in a diverse array of dynamic and advanced healthcare projects.

- Working Group members agree that this would not be a top-down, command-and-control process. Any plans developing from this Working Group must be market-based solutions, not edicts from government. Government needs to be an enabler not the driver of the processes.

- The goal of the statutory language (Special Act 16-20) suggests that the best course for the Working Group is to determine what project this group could collaborate on in order to break the well-established silos separating data generators and analysts from the cooperation needed to succeed in the 21st century data analytical world that has already arrived.

- S.A.16-20 focuses on developing collaborations in order to reduce industry costs and expand services to patients and customers alike. Reducing the "silo effect" that is present in this and many other industries, it is hoped that the data embedded in hospitals, insurers, and research institutions can be shared in order to expand and drive a new Connecticut economic base.

- Discussion: **What are the economic development drivers in health data in the state? What are the potential opportunities?**

    1. **Open Access to Patient Data** (with permissions) **available to patients, research institutions, and industry alike**
        - **Business assumption**: *Patients have the right to their digital health related data* – this is federal law; potential for state law; currently patients have the right to (inconveniently access) their data. There is potential for them to own their data. The goal is to give people a safe place to put their digital health-related data – and a way to share it, if they choose – and to encourage health systems to build trust and improve patient care.
            - Access to data should be uniform with uniform authorization that enables people to have a single username and password that works for all providers

- Any companies collecting health-related data on people in CT (laboratories, pharmacies, wearables) must provide the means for people to obtain that data digitally
- Security systems vital – protections must be in place to prevent inappropriate use of data, scams, ect.
- Access to data should be in control of patient; EHR vendors must comply
- Concern - protections for physicians sharing their personal notes – liability?
- Concern – ethical issues?
- Issue: "What is the record of truth?"
- Business opportunities to create applications for total access (not HIE)
    - see Blockchain data-sharing ["How the blockchain is changing money" TED]
    - The Massachusetts Green High Performance Computing Center (MGHPCC, http://www.mghpcc.org/) operates as a joint venture between Boston University, Harvard University, the Massachusetts Institute of Technology, Northeastern University, and the University of Massachusetts. It is open for use by any research organization.
- This is a huge issue that may be beyond the scope of government understanding or beyond any government authority. It is generally agreed that industry should attempt to cooperate in developing a solution before government chooses to regulate; *consumer health data exchange*" could make Connecticut a leader in addressing this fundamental issue in the United States, by sparking innovation based on participatory cooperation, collaboration, and a general sharing process among all industry players.

2. **Create a consumer-mediated information exchange** that empowers people to control their data and their health decisions, using cloud processing
    - How would claims data fit into this model, if at all?

3. **Personalized genomic mapping | Building capacity for personalized and precision medicine systems** – 3.5 million lives in CT – what if we offered that to every citizen? Cost – approx. $1,000 per person is a small investment (potentially) the state could make in its citizens; they could opt-in to any research or programs presented to them
    - The human genome study has become a primary driver of healthcare in this country and the world

- UConn recently awarded grant to study and pursue genetic counseling

4. **Build and Asset: Polypharmacy database –** as established by the VA with standards in place, expand and scale out this model to all patients in the state using prescription "fill data". (This is being done for opiates)
    - Patients opt-in
    - This would help prevent overprescribing
    - Potential to scale up this database even further to include more info of patient record

5. **Develop and implement innovative approaches to prevention and wellness**
    - We need a common definition of what this means
    - **Focus on community health centers** and implement processes for sharing data to increase efficiency of healthcare delivery with particular attention to **the social determinants of health** (behavioral health, social services, housing, domestic environment, substance abuse)

6. **Microbiome mapping – China has invested $9 billion in this sector**

    - The human microbiota, being the aggregate of microorganisms living in association with the human body, forming a microbiome that resides on or within a number of tissues and biofluids within the human body.
    - Studies have demonstrated that manipulation of these communities could be used to treat disease; The NIH Common Fund Human Microbiome Project (HMP) was established in 2008, with the mission of generating resources that would enable the comprehensive characterization of the human microbiome and analysis of its role in human health and disease
    - Human microbiota is the ultimate in preventative medicine, because it is noninvasive but can quickly reveal and in fact provide a medical solution to many problems before they even manifest as a disease or other condition. That makes such a project ripe for immediate action that would have a long-lasting permanent effect on what is clearly going to be a process that will have a giant impact on disease, health, and lifestyle management for many patients

<u>Technology Needs</u>:

- **Identify data storage requirements**, now and into the future, and suggest avenues for assuring adequate and reasonably-priced capacity for all industry participants;
- **Address the digital divide** (start with ZIPCODES) that exists in this state, analyzing its current status and assuring and adequate future,
    - **Identify the processes needed to develop digital equity** specifically for all healthcare patients across the state;

"We need to create something that goes beyond our borders."
We CAN cooperate.