CHDC Meeting Notes – located at CHDC online
Sept 28, 2016

Agenda:

1. Introductions
2. Review Opportunities Discussed
3. Polypharmacy Database (Amy Justice)
4. What is Prevention & Wellness?
5. Develop Precision Medicine Agenda
6. Other?
7. Next Steps

Please note: discussion moved off our agenda so notes reflect this.

Matt McCooe (CI), looking for investments opportunities for the under invested $200 million **CT Bioscience Innovation Fund (CBIF)**

- This working group may provide a resource for bringing entrepreneur, academics and researchers together with venture capitalists and other investors; maybe something more formal could develop in order to cultivate ideas that are not quite ready for a business pitch – a la "shark tank"; *Venture Clash*, Oct 20 event

- **Dr. Tom Agresta**, UCHC, discussion of potential for the development of an open access data playground

"**Data Playground**" – users share and access data as needed and agreed to by patients providing the data;

- **Current healthcare problems a data playground may help to solve**:
  - There are too many different ways health data is being captured and these systems are often not interoperable
  - Too often data becomes unwieldy and unusable by providers. There is often too much data available and it can overwhelm.
  - In general, EMRs are moving toward a common standard, so there is a real need to "mash up" the data for best value. (**See Fast Healthcare Interoperability Resources) FHIR**[1]

[1] https://www.hl7.org/fhir/ and https://www.hl7.org/fhir/summary.html

- Who owns patient data? Unclear. Patients have the right to "freely access" their data but this has proven to be very challenging to implement with any efficiency to scale.
- What would an open data playground look like? Multiple steps would need to be performed on data, including: gathering, curating and "cleaning" for mining,, allowing for people to perform predictive analytics and other analyses.

- **Concerns**: How to protect data and privacy issues? Insurance co's are required to share certain data points already – is this really a business opportunity? We are already working on the All Payer Claims Database (APCD) where self-insured can volunteer to participate, but progress has been very slow by the state; suggestion it may be better to start small and then scale up (i.e. **polypharmacy** data could be the beginning, or addressing **diabetes**); **major challenge to the group is to removing the barriers that prevent sharing data;** there are educational and access barriers – not everyone understands or has access to their health information, which exacerbates the health and data divide across the state; also - what are the legal barriers to sharing data? We will need legal advice to set a path forward. (**Takesha Everette**, Health Policy Solutions)
- **Vicki Veltri** (CT Health Policy Officer) identified potential model to use: the **MA data warehouse and Hawaii's as two examples**[2] that allow for analysis and helps drive government policy-making. (note: MA was also recently hacked[3]) Also see the **Framingham Study**[4] as a possible research model to replicate

- **Potential goals of an [Open Access] Data Playground:**
  Foundational premise: EHR data must be available, discoverable, and understandable. To support automated clinical decision support and other machine-based processing, the data must also be structured and standardized. A data playground could:

  - Provide access to data that will benefit all participants in a safe environment for analysis? State policies would have to support this in order to maintain safety and security
  - Establish an open access platform that could target precision medicine opportunities
  - Create consumer oriented apps to access the data in a significant and meaningful way? There are many consumer apps in the

[2] MAEHC - http://www.maehc.org/ Hawaii Health Data Warehouse - http://hhdw.org/
[3] http://www.securityprivacyandthelaw.com/tag/massachusetts-ehealth-collaborative/
[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159698/

marketplace right now. How would any new app be different, urgent, and unique?

- Create platforms for actionable data so that healthcare providers have access to data that is usable and in real-time.

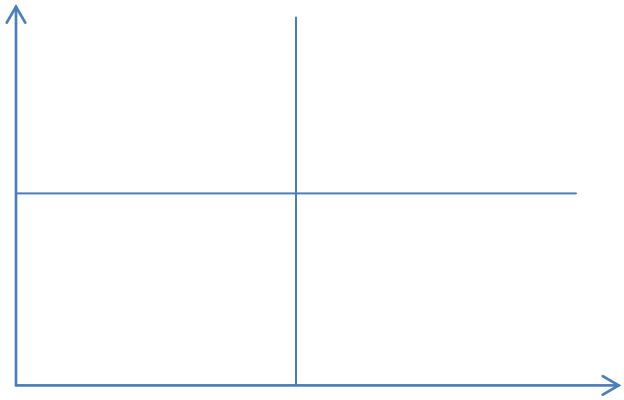
Outstanding questions on the DATA PLAYGROUNDto be continued: Do we need to have one or more overarching goals that the working group needs to embrace before we create something like this? Or should we allow for synergies to take place among group members collaborating around common goals over time? Are these mutually exclusive or can we and should we do both? As part of our process, we need to identify the financial and health benefits and costs of such a playground.

ACTION: Send out questionnaire to gauge opinions of participants regarding the DATA PLAYGROUND, recognize this may be premature…

Regarding potential CHDC opportunities: A potential tool for decision-making**. What is the value proposition? Use this matrix:**

Pay-off:

- Invention/$
- Health outcomes
- Lower disparities
- Other



Effort/Risk:

- Cost
- Legal
- Technical

Prevention and Wellness

Most agree that investing in strategies and business opportunities that target prevention and wellness and treatments (i.e. for diabetes) the long term costs of not doing anything outweigh the short term costs of investing in potential solutions. Tom Woodruff describes the state HEP program as exemplifying this.

Tom Woodruff (State Comptroller's office) on Prevention and Wellness - the Health Enhancement Plan (HEP)[5] requirements include preventative physical and dental exams as well as preventative screenings; disease counseling also required as needed. The program succeeds because:

- Workers are "incentivized" by way of stiff financial penalties for *not* participating
- Workers (most – is this true?) can take the time off for their medical appointments

  There are four levels of prevention[6]:
  - Primordial - actions and measures that inhibit the emergence of risk factors in the form of environmental, economic, social, and behavioral conditions and cultural patterns of living etc.
  - Primary - to prevent the onset of specific diseases via risk reductio
  - Secondary - includes procedures that detect and treat pre-clinical pathological changes and thereby control disease progression
  - Tertiary - seek to soften the impact caused by the disease on the patient's function, longevity, and quality of life

ACTION: Next meeting we will address prevention and wellness through the lens of precision medicine.

Polypharmacy Database (Dr. Amy Justice)

Review of proposal

- Expansion of opioid database to include all FILLS. This is in use in 23 states connected to a database. Patients do not have access to that database, but that it could use well-conceived apps to provide greater access for purposes such as drug interactions relating to multiple medications, and scheduling of prescription use and management.
- Current database is downloaded nightly, and cost only about $170,000 to initiate.
- Doctors can access this database in their offices, the system to use it is regarded as clunky, but the idea has great merit.
- There is some question as to Dr. liability if they fail to use this database, which obviously operates as a penalty but may incent greater use.
- Surescripts software app not universally well-regarded, but features nightly downloads and does provide electronic healthcare records access, particularly for prescriptions held in the database and accessible in the context of doctor workflow.

[5] http://www.osc.ct.gov/empret/healthin/2011hcplan/HEPprogress/hepindex.htm
[6] http://phprimer.afmc.ca/Part1-TheoryThinkingAboutHealth/Chapter4BasicConceptsInPreventionSurveillanceAndHealthPromotion/Thestagesofprevention

- **Potential Opportunity**: We could develop a "mash up app" - an improved product that would allow for patients to check Surescripts AND have the added benefit of a visual reference for drug adherence or action steps to be taken in the future. However, there is a critique of Surescripts existing interface and its limited capacity may not scale up easily for the level of project that the group is considering.

  Should we bring in Surescripts to discuss? (Lisa Stump will follow up)

- **Further considerations**: get clarification on who will follow up
  - Need cost/benefit analysis – include legal and financial; needs analysis
  - *Use matrix tool above to perform this analysis*
  - What is the competitive ecosystem? Scripts may already be doing this
  - How to attract the investment capital to implement
  - Need to know what would be operations and management expenses For instance, the state currently operates the opiate database, and if that were incorporated into a new, larger private database than the state would be able to avoid the cost of operating its own database.

Concerns over vision and ability to take on all of these ideas. "We need to boil the pot, not boil the ocean." Consensus that we need to ensure insurers, providers, and researchers agree we can work together.

Potential opportunity invite physical fitness industry into the CHDC as it is an important industry in the health ecosystem. CHDC could address injury prevention, targeted medications, physical therapy and fitness programs. (Mike Critelli)

Potential opportunity: develop applications to protect and secure data (Dan Salazar and Ellen Katz)

Would this database complement the data playground? Not clear.

Suggestion for immediate goal: develop the concept, implement a pilot program, provide a demonstration of the potential in an incubator – this will help create a vision and clarify goals and value proposition.

To be continued!

Next meeting: Tues, Oct 11, 9am – 12noon at Community Health Center, Middletown

PP/WV