

Re-cap of emerging themes:

- 1) Healthcare is a major economic development driver in the Connecticut economy
- 2) Sharing health data across systems is critical
- 3) Precision medicine has enormous potential
- 4) Social equity and health literacy are major challenges
- 5) Increasing participation rates in prevention programs has significant financial impacts
- 6) Connecticut has vast resources that are silo-ed and underutilized
- 7) The transition to a value based health care system is under way

The Working Group has preliminarily established five areas of focus:

- Growing our prevention and wellness programs;
- Building our capacity for personalized and precision medicine
- Launching new and innovative ways to access healthcare data
- Expansion of VA polypharma database
- Development of health analytics/informatics sector to support all of this work
- Patient-owned data initiative

1. Precision Medicine presentation by Joan Grand (MITRE) and Wanda Mantalvo

President Obama's Precision Medicine Initiative (PMI) – 10 year program

- **Mission: to enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care.**
 - Goal: 1 million or more volunteers reflecting diverse backgrounds
 - **Partners:** FQHCs, including Community Health Center, Middletown; NIT, Dept of Defense, NIH – want to link environmental, genetic, and behavioral factors; PNI Cohort Program partners involved every step of the way – 11 organization already chosen
 - FY16: \$130 million, FY17 request: \$230 million
 - Currently two methods of engagement – direct volunteers and Health Care Provider Orgs
 - All data is open access
 - **Selected scientific opportunities:**

- Develop quantitative **estimates of risk** for a range of diseases by integrating environmental exposures and genetic factors
 - Identify the causes of individual variation in response to commonly used therapeutics = **pharmacogenomics**
 - Discover **biological markers** that signal increased or decreased risk of developing common diseases
 - Develop **solutions to health disparities**
 - Use **mobile health technologies** to correlate activity, physiological measures, and environmental exposures with health outcomes
 - **Empower study participants** with data and information to improve their own health
 - Create a platform to enable **trials of targeted therapies**
- Data has been and is being collected – modules are under development; will there be occupational, environmental, behavioral, sexual health risk, sleep patterns, medications – these are all potential corollary info points.
 - Public opinion survey about the PRI show broad support, particularly regarding **people’s potential for learning about one’s own health information**
 - Established program infrastructure:
 - Data and Research Support Center (DRC) at Vanderbilt University | Broad Institute | Verily
 - Biobank – Mayo
 - Participant Technologies Center (PTC) – Scripps, Vibrent Health
 - Health Care Provider Organizations (HPOs) – 11 awards, including CHC, Middletown
 - Other Highlights:
 - Established governance of the program (Executive Committee, Steering Committee, and 11 Working Groups)
 - Drafted informed consent language and initial set of questionnaires for IRB review
 - Gathered public input to inform communications and outreach plans, focused on participant experience
 - Developing plans for baseline physical evaluation and biospecimen collection
 - Building IT interfaces for data transfer and documenting and testing security safeguards
 - Creating one of the world’s largest biobanks I history for 35M+ vials
 - Plans for launch and beyond:
 - Will launch when ready and right

- Phased implementation as we pilot, iterate, and scale
- Anticipate 3-4 years to reach one million
- Over time, anticipate new technologies, protocols, and assays
- Will work toward interoperability with other cohorts to the degree possible
- Audacious goals to help make this happen:
Through PMI Cohort Program, we aim to generate:
 - A new model of research based on collaboration among researchers, providers and participants
 - A rich resource of data, including biospecimens, to help accelerate research advances
 - Increased knowledge leading to individualized care and improved health for future generations
- Discussion:
 - Should CT mirror this and create our own PMI internally? How might they intersect with each other? To be continued...
 - How do we empower our own constituents? We need to work with PCPs and community health workers to educate them and their patients about the benefits of having your code done. "Primary care happens at home."

PMI Cohort Program: <https://www.nih.gov/precisionmedicine>

Would a **Connecticut Center for Precision Medicine** or a **Connecticut BIOBANK** complement **PMI** or compete with it? Not clear

Possible Strategy:

PILOT Genomic Mapping Benefit for ERISA companies and state employees:

Connecticut BIOBANK - "better living through genomics." (Mark M)

- Anthem, Cigna, Aetna, CT State employees, hospitals (?) will consider a pilot of a genomic mapping benefit
- Murat Gunel: Yale is open to any investigations across the nation into the data, including sequencing transparently for such healthcare researchers and other institutions. Mount Sinai and JAX would add an even more robust partnership
- Gradual increasing population to include Medicaid population (in partnership with DSS) and other ERISA companies.

Challenges/Concerns:

- Patients don't know enough about genomic/precision medicine to buy it - we would have to have a robust marketing and education plan to get this going
- Wanda from PMI says patients are reluctant to carry around their data on their phone - trust issue
- Securing data is critical for trust and patient safety

- **Christine C:** 70% of Connecticut businesses are “self-insured.” With regard to privacy, which she stated was a key issue that needs to be acknowledged and addressed, **the state’s “advocacy community” needs to be identified and communicated with in order to reduce their concerns regarding “privacy encroachment.”**

Action Steps: Yale and Anthem will outline a “proof of principle: proposal for initial partnership; “the power of the group could be consolidated into a focused path toward commercial success.”

Responsible: Murat Gunel (Yale) and Peter Bowers, Anthem - due Oct 28th

FYI - The Geisinger organizations research and provider network has been repeatedly cited by the group, and in this instance it was noted that they were willing to spend money to make money, and not accidentally the idea that breast cancer incidence is very low in the area in which they are serving. [Http://www.geisinger.org/for-patients/services-specialties/cancer/pages/research.html](http://www.geisinger.org/for-patients/services-specialties/cancer/pages/research.html)

2. **OPEN DATA PLAYGROUND:** add a question that’s more relevant: *what do you want to do with the data?* Need to look at risk adjustment models;
 - Data is the new oil, a virtual asset – but patients must remain at the center
 - Harlan K: Connecticut is big enough a market to be consequential, but small enough to be able to manage the collaboration to organize and use such a database. If data is the new oil, it would be important to develop ways to “pump it.” Other states are working on this (Colorado) and could conceivably pass Connecticut by trying to find partners and develop infrastructure to create and bind a database. Connecticut does not need to replicate of another state, but should focus on empowering communities of all kinds, including the education of those communities is the value and uses of such a database.
 - Murat G, Todd A, Mark M: Do we need to target a disease such as cancer and start a pilot study to incent investors to join in seeking financially rewarding cures?
 - Mike C: Do we need use cases or a niche in order to create interest? i.e. sports medicine – Not clear yet
 - Murot – “no further investment is needed to create genome machinery, but that investment is needed for developing a market for analytics based on established databases and methodologies.”
3. **POLYPHARMA database:** Amy Justice – expanding the VA model could start as a small initiative that could be scaled up. Need to flesh this idea out in terms of implementation and model. This model has the potential to create a virtuous cycle in

which clinical trials involving patients permitting the use of their data will in turn create the commercial database. (Like Stone Soup story)

Action Step: Amy will connect with Marie Smith at UCONN to develop further
Report back on Oct 28th

4. EXPANDING THE FIELD OF HEALTH INFORMATICS/ANALYTICS

- CT has the opportunity to expand the field and grow the sector because the need for health data analyzers and curators is and will be great. (Tom Agresta working on this proposal – will bring proposal at upcoming meeting);
- PP - Need to bring in the community colleges on this as well
- **Need for Genetic Counselors** - Todd A: This new educated staff cohort would have the ability to best communicate with patients to help convince them to contribute their data by their permission, as well as helping to make the complex data digestible to a far broader population. This will in turn contribute to making Connecticut the data analyzing center of the world, with a focus on genomic medicine, which has a \$1 trillion future. **Need to build the education pipeline to fill the needs of the future.**
- **How to build the talent pipeline: Joe M** – perhaps after training at a program such as that offered by UConn, a genomic counselor agreed to work at a Connecticut institution or company for a period of five years, and their educational expenses would be essentially “repaid” by tax expenditures to their benefit. He noted that this is an exciting concept, but he asked the group whether the members of the collaborative would work together as funders, along with the state, in an attempt to sell the concept to taxpayers as a productive experiment for the future of the state.
- Peter Bowers favored the concept of building business plan incorporating the genome counselor education system in order to staff ongoing operations in that regard. He suggested that that such a group would advise nationally via a virtual (telework) network that should be developed across the state. Caution – don’t want to boil the ocean

Action: Reach out to UConn Genetic Counseling Program and bring them in
(Polly) Due Oct 28th

Bruce Carlson added that planning for the collaborative venture to be implemented via incremental steps will require carefully delineated timeframes and milestones to accomplish the goals along the path. Masselli stated that the project eventually decided upon by the group will require a disruptive idea to make Connecticut unique among the states

Other resources:

CT Healthcare Cabinet October meeting [here](#)

Next Meeting:

Date: Friday, October 28th

Time: 9am-12noon

Host: Todd Arnold, Mount Sinai

Location: Blackstone Library, Branford CT

PP/WV