

CT Health Data Collaborative
Nov 1, 2017
Community Health Center, Middletown, CT

Meeting Notes

Attendance: Joe McGee, Senator Joan Hartley, State Rep. Cristin McCarthy Vahey, Allan Hackney (CT State HITO), Vicki Veltri (CT State Chief Health Policy Officer), Mike Hyde (JAX), Wanda Montalve (CHC, *All of Us*), Mark Masselli (CHC, CEO), Murat Gunel (Yale), Mark Schaefer (CT SIM), Deb Hutton (CIGNA), Erin Smith (CIGNA), Tom Agresta, (UCONN), Judy Brown (UCONN), Maria Gyure (UCONN), Bill Vallee (OCC), Elin Katz (OCC), Polly Painter (SDO), Elliot Ginsberg (CCAT), Aimee Monroe Smith (JAX), Rick Strauss (CASE), Terri Clark (CASE), John McCreight. (Others calling in ?)

Summary Updates: Please see slides for more information

Wanda Montalve, CHC and *All of Us*, national Precision Medicine initiative

[Slides unavailable due to privacy concerns]

Currently in beta phase moving to alpha phase to roll out protocols to bring more people into the study; focus on diverse populations (which makes this unique to other PM programs); there are multiple state and federal agency partners involved with broad bipartisan support at all levels of government. To participate, there are several levels of privacy and security built into the program, with an emphasis on safety; Patients have access and control of their own personal data; data anonymized for more broad research purposes in order to make it fully accessible; beta phase brought 5035 participants with full participation the goal (“full” meaning all levels completed.) Outreach has been minimal at this stage and they expect the program to really ramp up once they put more effort into promotional outreach during the actual roll out; **Target Launch is MARCH 2018**; PPI surveys and wearables also collecting data for each participant; bilingual staff with shared scripts very helpful; Participants understand the results of this research will have broad implications for healthcare, for their families, and for themselves – participants seen as full partners in the program. MITRE just did a site visit to CHC and endorsed their process.

Mark Masselli, CHC update on the Weitzman Institute’s “ECHO” program

[See slides]

Using “ECHO” to tackle hotspots, with focus on HepC, HIV, Complex Care Management, Complex Integrated Pediatrics, Buprenorphine, and Pain; CHC is 1 of 7 centers funded as genetic regional center; there is a robust learning network all across the country participating in the program; there is a great need for genetic counselors to work with primary care providers to communicate with patients; there are many opportunities for training, particularly online; there is currently a collaboration between Yale and UConn to help meet the need; still, the need is great and we are at the beginning stages of being able to meet the needs that continue to grow as genetic testing grows exponentially. See New England Regional Genetics Network (NERGN).

Mike Hyde, JAX Forum on Healthcare Innovation highlights

[Slides available]

Another very successful forum. This year Frances Collins was keynote. Among highlights and takeaways:

- 1- New technologies:
 - a. CRISPR-Cas9 (although there is some pushback on the effectiveness of this, may be too early to say genomic sequencing is cost-effective; this was limited to leukemia); Geisinger did similar test of 57 medic. actionable diseases of 5700 – 3.5% had a medically actionable variant.
Ultimately, we need to be able to say that the value of sequencing healthy patients is a worthwhile investment. We need to separate the diseased patients' results from the healthy people's results to know this.
 - b. single cell genomics
 - c. microbiome
- 2- All of Us – the number of people getting genetic testing done is growing exponentially; “recreational genomics” is drawing people in; many still don't know the medial, population health benefits yet;
- 3- Study on aging by UConn/Einstein college partnership – **Is aging the real disease?**
- 4- Companies to watch:
 - a. **Helix** provides low cost “consumer controlled” sequencing;
 - b. **Genome Medical**: scalable counseling, linked to records
 - c. **ActX**: screen for medical issues, drug reactions and link to medical records
- 5- Pioneering medical systems are linking sequence data with patient records for prediction and diagnosis:
 - a. **Colorado, Vanderbilt, Geisinger, Innova, Intermountain, Mayo and many others**
 - b. Attacking the problem of interoperability
 - c. Next challenge: demonstrating the economics of predictive screening
- 6- Major takeaways:
 - a. Collins: The age of precision medicine is here
 - b. The field is moving fast: we must move fast, too.
 - c. Big data is ubiquitous, analytics and tools are key
 - d. Entrepreneurs are building the components of a new medical infrastructure
 - e. Many small successes are as good as one big one
 - f. **Prediction will soon equal diagnosis in value**

Other: Look for upcoming JAX research partnership with NIH, 2K-3K people doing genomic sequencing against 59 medically actionable genes, with genetic counseling and tracking through insurance co's. Insurance companies keeping close eye on these results.

Vicki Veltri, CT State Chief Policy Officer, LGs office

[see slides] Legislative update –

- 1- Legislation this year implemented the go ahead for consolidating offices and programs into the Office of Healthcare Strategy so that, as a state, we can plan for comprehensive healthcare policy over the long term, including:

- Developing and implementing comprehensive and cohesive health care vision for the state including coordinated state health care cost containment strategy
- Directing and overseeing the APCD and SIM
- Coordinating the state's HIT initiatives
- Directing and overseeing OHCA
- Convening forums/meetings with government and stakeholders including CHIE to discuss and develop effective cost and quality strategies
- Advised by Healthcare Cabinet – stakeholder group

Ultimately, we will need to use predictive modeling in order to gauge cost to outcomes for a value-based system. Feds are most interest in VB outcomes. **SIM would like to pull together a small group to bring in genetics into the work they are doing.**

2- Breakdown of functions of the OHS:

- The OHS provides the state's first overall framework for health policy strategy
- Allows for unified data-driven policymaking and coordinated cost containment strategy decisions.
- Central coordinating structure to develop health policy to improve health outcomes and investigate or limit healthcare cost growth across all sectors whether private or public—hospital, physician and clinical services and prescription drugs.
- Brings together critical data sets and health information exchange efforts
- OHCA develops a statewide health plan based in part on up-to-date hospital data sets and practice information. It also runs the certificate of need (CON) program that determines appropriate siting and need for various healthcare services and facilities around the state
- The State Innovation Model (SIM) aims to improve healthcare quality, improve population health, eliminate health inequities and reduce costs through reforms to the delivery system, the use of alternative payment models, value-based insurance design, and population health planning. The SIM is a multi-payer initiative and works across DSS, DPH, DMHAS, CID, DCF, UConn, the Comptroller's office, employers, carriers, providers and advocates.
- HIT and APCD – key enablers of reform work.

Allan Hackney, HITO

[see slides]

Describes how the HITO will function as the hub for the state's health data for shared services, eventually combining data from the APCD, Medicare, and Medicaid. APCD data available for release will include all enrollees, non-ERISA. Some ERISA companies are voluntarily contributing their data – see Cigna; medical claims, pharmacy claims, including provider/facility directory.

UConn is designing the infrastructure (see slide); We need “agile programming” to make this work with 2 key attributes: TRUST and NEUTRALITY.

Other state may be further along, but we have a lot of quality data in CT, so we aren't far behind.

European Privacy Rules will come out in May, and it is likely that the USA will follow their lead. Under the Trump Administration, rules are relaxed at the federal level, so states will have to go it alone and pick up the slack. Most agree there is value in doing that.

Elin Katz – OCC brief update

Newly passed budget ensures OCC and Office of Broadband will remain intact; their goal is to make broadband affordable and accessible to all people in CT. With the exponential growth of health data coming from genomics, the state must be ready to step up and provide the necessary infrastructure the market will eventually demand.

There are municipalities doing this on their own – the newest being East Hartford. The Town of East Hartford has entered into a development agreement with SiFi Networks to install a high speed fiber-optic network to all corners of East Hartford. Funded entirely by SiFi, this project will be the first network of its kind in New England, and will provide high speed broadband internet to all East Hartford residents and businesses through their Internet Service Providers.

[\[See more info here\]](#)

While the CHDC hasn't addressed specifically how the state will respond to the growth of genomic testing and the data that will result, it's only a matter of time.

Joe McGee – discussion of building a Northeast Bioscience Corridor

NYC's strategic plan suggests the city does not have the capacity to respond adequately to the predicted growth of the city over the next 10-20 years, as reported at our last meeting by Carolyn Grossman Meagher, their regional development coordinator. The growth of the bioscience sector is a big part of that. The state needs to respond with a compelling argument for any expansion to move our way. CHDC will establish a working group to address this – very timely issue. Need to respond relatively quickly. Next steps: Joe will start making calls about participation.

Next meeting :TBD

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