

Date: Wednesday, December 7, 2016

Time: 2pm-5pm

Place: Yale Medical School, Beaumont Room, 333 Cedar St., New Haven

Host: Amy Justice, Yale Medical School, Professor of Medicine (General Medicine) and of Public Health (Health Policy)

Polly Painter opened the meeting and greeted the members of the CHDC, and asked Dr. Amy Justice to introduce herself as host of this meeting.

Amy Justice has studied predictors of survival and quality of life and is expert in the development, validation, and evaluation of multivariable prognostic models. She has published over 200 papers and served on thirty expert panels addressing issues of understanding and improving clinical outcomes in HIV infection. has conducted research focusing on outcomes in chronic HIV infection for over 25 years. She is the Principal Investigator on the Veterans Aging Cohort Study (VACS) considering the complex roles of aging, symptoms, medical treatment, adherence, patient-provider relationships, disease severity, and medical and psychiatric comorbid illness in determining survival and quality of life for people with HIV infection. VACS has received 15 years of funding from NIAAA and was recently funded as a consortium by the National Institute of Alcohol Abuse and Alcoholism at NIH.

Draft Proposal Review

General theme that the CHDC will be addressing, to **pursue the statutory request for economic development and jobs creation relating to an innovative and transformational approach to health and healthcare to deliver more effective, predictive, and precise health care to each individual.** This approach to medicine and health seeks to define well-being and improve health care—from prevention to diagnosis to treatment—for each individual, based on their genomic data in relationship to what is known about that person's unique characteristics, circumstances, and social determinants of health.

Mark Masselli suggested that the proposal should operate on a multitiered structure, much like an accordion, with entry tiers for lay persons and in-depth tiers for more professional partners.

Discussion on naming: Personalized vs. Precision vs. Medicine vs. Health

Tom Agresta, noted that as a “family doctor” he favors “**personalized health**” since he didn’t believe that “precision” doesn’t sound like “help,” but more like science. it was essential to put the patient at the center of healthcare no matter what terms are used to define the mission of the CHDC. Others, including Murat Gunel and Tom Peters, noted that the **NIH appears to presently prefer “precision.”**

Mike Critelli noted that 80 to 90% of healthcare takes place outside the formal healthcare system. **CHDC’s mission should promote the goal of being unique in the US, empowering millions of people as patients,** i.e., being a distinctive process, a “game changer,” and not just “me too.” Mike referred to the concept of “**quantified self**” that allows for data to be captured in multiple new ways, such as through apps, smart phones, and other feeders of data from patients.

Amy prefers “**personalized**” but that it appears that word for this process is “on the way out.” A further discussion ensued regarding the contemporary title, “**All of Us-Connecticut**” is a possibility. CHDC will need to develop stories, such as a salt sensitivity leading to hypertension, and the research technology developed by the CHDC could provide a patient with a quick profile to determine an individual’s salt sensitivity. **Humanizing genome mapping is crucial.**

Action step: To be continued. There was no consensus on this right now; but rather - **decision to focus on vision and mission to inform the name.**

Who is the audience for our proposal

General Assembly, potential investors, and members of the three key groups of the CHDC partners, insurers, providers, and researchers.

Mission of the CHDC is to create a collaborative of with the goal of using health care innovations generated by the partners to create a new economic driver for jobs creation in the Connecticut economy.

Wendy Sherry noted that the proposal could **use more language directed at that mission** to make certain that those goals remain at the center of the proposal and the activities of the CHDC. Joan Hartley agreed that economic development and jobs creation form the nexus of the entire

project. Tom Agresta stated that the **CHDC is composed of two pillars: research and investors such as insurers and pharmaceutical companies that will become engaged in patient outcomes through genomic research and technology.** Tom further noted that it will be important to consider future multiple funders, in addition to the potential NIH grant being discussed today.

Action step: Tom will forward information about potential pillars and info regarding Learning Health Community.

Murat Gunel suggested that the **proposal needs an executive summary** to ease lay readers and others into the topic and our conclusions. He sparked a discussion of the recent passage 94 to 5 by the US Senate on 12/7/16 of the 21st Century Cures Act, health care legislation that had been overwhelmingly approved by the House last week that would increase funding for disease research, address weaknesses in the nation's mental health systems and vastly alter the regulatory system for drugs and medical devices. The bill presents potential benefits for nearly every American whose life has been touched by illness, drug addiction and mental health issues.

Mark Masselli noted that the **21st Century Cures Act refers to "precision."** The actual process will consist of linking big healthcare data into both providers and research, accommodating patient privacy goals, without creating a "cost pit" by creating a series of ongoing requests for further tests and treatments. Joe added that the program must address equity among all communities, including low income and rural.

Peter Bowers noted that from the insurance perspective as trustees for patient funding ("stewards of other people's money"), Connecticut is a high-cost state and that therefore insurance funding is tight in the state. He remains excited at the prospect of the Collaborative's ideas becoming a profitable reality, but that it probably does not make sense today from the insurance point of view. Peter cited to the Framingham project which he declared "set the stage" for projects such as this collaborative, and that the CHDC partners have recognize that **today's market requires new avenues of thought and practical implementation.** Clearly, Peter stated that **the creative approaches being utilized by the CHDC partners, such as applying for NIH grant funding, represent a great start and that the project is clearly worth the participation of all partners going forward.**

Murat agreed and noted that New York and California are not pursuing this direction, and that therefore the CHDC has a unique spin on its direction, and has access to over 3 million lines for sampling. He noted that **any practical resolution of this will save money for the insurers while preventing disease. It is important to not attempt to “boil the ocean” but to develop detailed and explicit procedures for proceeding to the recognized goals of the group.**

NIH funding for the future will depend on strength of our collaborations

Murat moved on to the NIH grant discussion, noting that the grant application itself will require “cohorts” for spring 2017. Polly asked Murat what he means by “cohorts,” to which he responded that he means partners and entities in cooperation through the collaborative. He further noted that Yale will be applying on its own, but the idea of **a statewide collaboration and partnership with as many partners as possible would make the application form are likely to be successful in obtaining grant funding.** What makes our group strong?

1. Potential cohort populations:

- Tom Woodward of the Comptroller’s Office, possible demonstration project with DOT/state truck drivers and incidence/treatment for diabetes
- Insurance companies as cohorts supporting the NIH application: “cohorts” could mean merely a letter of understanding from the company indicating that it fully intends to engage in this process.

2. We can produce a methodology or concept for the application, in combination with letters of agreement from the partners to work on this project.

3. Yale, ([Rick Lifton contact](#)), is a self-insured entity, University system provides incentives such as health club memberships and a general wellness program for employees, with a 70% participation. NIH relies on the track record of the applicant in large part, and that the grant would probably not be graded by its weakest link. In any case, he recommended that since the RFA will not be released until the spring, **there is time to conscientiously research and develop the best application possible. (Murat G)**

- 4. Diverse communities and participation in the project, with notice of that intention contained in the application, will be a necessity.** The application needs to present a sustainable, distinctive proposition. (Tom W) **Integrating a nondiscrimination policy and a broadly diverse community of partners will be central to the NIH application process.** (Tom A)
- a. Need to define what parameters and definitions would be used for “diversity” and how could such communities be engaged in the actual collaboration itself? (Todd A)
 - b. Patients need to be represented - NIH has distinct focus on the community. (Lisa K) **Everything the collaborative does must be “person centered” and that all activities need a strong engagement for all the partners as well as complete buy-in from consumers.** (Polly P, Tom W, Tom A)

In order to position ourselves strongly, we should consider organizing and structuring ourselves in alignment with NIH appeal. (Polly)

Initial application requirement will be to create the organization, demonstrate the cohorts and funding opportunities, followed by express descriptions of the scientific approaches that will be utilized by the collaborative. (Tom A)

5. Potential demonstration projects should center on CT specific challenges:

- a. Our state has **a** very high rate of asthma and diabetes in its cities, very costly diseases that rely on Medicaid funds for care and treatment,
 - b. The collaborative could have a positive effect on these types of problems. Connecticut has an aging population, among the highest of all states, with a higher levels of cancers per population density in accord with that ratio.
 - c. Also, potential demo around mental health and substance abuse, also high in the state
- 6.** Connecticut has begun to implement **genomic counseling** as an academic pursuit and a workforce development idea, which should also be integrated into the application. **“Cambridge and Boston are years ahead of Connecticut” in general, but that the integration of industry, providers, and research institutions of the caliber**

that exists in Connecticut will be the differentiating factor that could lead to a successful application. (Murat)

In particular for UCONN, the educational rewards for the University could be a game changer, participation in the bio-bank would be a definite leg up, and the subsequent research could have a substantial effect on the University's profile. (Tom A) Also, **UCHC would be key to the application with its statewide presence, with its medical and dental schools, and that even 1000 patient samples would be useful to the effort.** (Tom W and Tom A) UCONN name would have a substantial and positive effect on the application. (Murat)

7. If Yale leads the application effort it will be extremely positive to demonstrate that **all partners bring individual strengths to the project**, and that everyone involved understands that it will be a win-win for all as a group. **By leveraging sampling, screening, and an ultimately sequencing and informatics among all the players, utilizing clever methodologies to show the contribution and the returns each partner expects to receive from the project, the NIH grant application will be successful.** (Todd A)

"It takes a village" and CHDC has become the village for this collaborative. (Lisa S) **Silos have fallen away and everyone in the group recognizes that this is not an individual initiative.**

Ultimately that the "roof will be held up by other economic opportunities" yet to be discovered by this collaborative. (Mark M) The NIH application will not only serve to generate funding for projects going forward, but will demonstrate to the state government that **private funding and efforts are being merged into a collaborative with a strong mission and clear goals.** (JoeM)

The application could draw in new players to the collaborative, and the "ask" must be clear and succinct, and further the value proposition for each player needs to be clearly demonstrated. (Elliot and Wendy)

Innovation and participation in the collaborative by one entity will benefit not only that entity, but will benefit all the partners in the group. For example, informatics and engineering could easily serve as the "secret sauce" of the Connecticut collaborative. The question of how to develop a statewide economic driver and jobs creating structure requires a clear pathway to ensuring that academic research innovations are

implemented by leaders in the marketplace for healthcare provisioning.
(Amy J)

Is legislation needed to advance the CHDC?

It will be important to demonstrate positive and sustainable returns on investment by the players around the table, not to mention the state of Connecticut itself. (Joan H) It is essential that we build a strong and positive marketing profile that can be demonstrated to the legislature to get the members on board. Engaging Department of Economic and Community Development (DECD) also important in coordination with CI.

Action Step: Legislation needed to prevent discrimination using results of genome mapping. (Polly)

Insurance companies should feel comfortable with participating as a cohort in the application since she believes that if her insurance company offered her an incentive to lower her own costs, which coincidentally would lower the costs for the insurance company, that would be a win-win for all parties.
(Lisa S)

Role of Insurance Companies:

- CIGNA, they would not be reaching out to insured customers of their company, but more likely they would be attempting to act through the employers of those insureds. (Wendy S)
- Insurance companies would probably be willing to incent their own employees to participate, and that such employee options could probably generate 5 to 6,000 samples a year. Discussion ensued regarding what level of payment from the NIH grant would be possible to initiate the sampling process.
- “Additional testing” or “over-diagnosis” is a central concern for the insurance companies and other funders. **Academic groups could certainly help by establishing guidelines and rules to produce evidence-based medicine they would balance the need for testing and treatments for patients while avoiding over-diagnosis and duplicative treatments.** (Amy, Tom A, Joe)

Other Support for NIH Grant application:

- Seed money may be required to start the application. What other sources could be tapped in order to provide this financial foundation? Connecticut Innovations, and NIH, and of course insurance/Pharma partners may also be able to contribute, while research institutions such as Yale and the Rockefeller Foundation may also weigh in with funding.

Introduction of Governance Structure

How will we organize and govern ourselves? (See handout) Breaking down silos:

- **Top most level be focused on innovation generation and management processes that will translate into practical uses to drive improved economics and jobs for the state.** (Amy and Murat) Connecticut needs to build a unique data set that can be profitably supplied to potential clients of all kinds, being the only state in the union that has such a database.
- **CHDC should perform the role of being a conduit for communication among all the partners in the collaboration.** (Polly, Amy) It is essential that each player recognize that the various elements that will be developed by the collaborative be equally shared and accessible to and by all participants, being essentially a “learning healthcare environment.”
- CHDC could facilitate networking and relationships; potential steering committee at the top of the organizational chart should be conscious of making certain that the right people are in the room at the same time when organizational decisions are made.
- CHDC is not a government agency, but a facilitator and enabler of business development. (Joe M) **Connecticut needs to streamline the process from research to business implementation in order to get things done and achieve practical goals.**
- Could meet quarterly, sharing information and processes, member driven, with modest but useful dues paid, in order to create a platform to accomplish projects of public policy goals. (Joan)
- **May be necessary to create an unincorporated association allies** the union and interoperability of the diverse members of this collaboration. (Elliot)

- EX: Massachusetts High-Tech Council through which corporate CEOs control for ideas, based on science and research, and only until we reach that level where “angel investors” or a “shark tank” environment where ideas can be pitched to investors will this group develop the economic drivers toward which we strive. (Tom P)

Including Venture Capitalists and Investors in CHDC?

(Joe) We’ve purposefully held off including investors until the basic framework and foundation have been developed. We’ll bring them in once our structure is more certain. Of note: **Ventured investors are indeed very interested in hearing what this CHDC group may propose for economic development and jobs creation.**

The strength of CHDC is the “**net of shared resources**” among the collaborating partners. (Amy) This group has the potential to “**see certain medical important genetic markers in a person’s biological profile.**” **The profitable result of identifying such genetic markers has exponential capacity for profits and healthcare rewards. The initiative and momentum that has been generated this far must be sustained in order to achieve the goals that seem so closely within grasp.**

Crystallizing a Model Framework

California and Québec models move toward economic development and jobs creation. While in Innovate UK and the Massachusetts High-Tech Council gave a nod toward economic development, they were not successful as the CHDC has the potential to become. The time is come to involve the investment community with the critical mass has been generated by the development of the CHDC. (Tom P) Perhaps it’s **time for business innovators to enter our workspace and collaborate with us to determine what, if any, of the innovations that we believe are presently on the horizon, will work to create economic development.**

Connecticut Innovations was interested in pursuing this (Matt M) this High-tech innovative companies of all sizes operating in Connecticut, could certainly make a strong contribution to the next phase of the CHDC evolution. (Bill V, Richard S) Big Pharma will need to be included into this project to add a very vital critical mass.

- *Bill Vallee/pp*

Attending:

Tom Agresta –UCHC

Todd Arnold -Mt. Sinai

Peter Bowers –Anthem

Christine Cappiello - Anthem

Mike Critelli – Dossia Consortium

Aimee Monroy Smith – The Jackson Laboratory

Elliot Ginsberg -CCAT

Murat Gunel - Yale School of Medicine

Richard D'Aquila - President, Yale New Haven Health

Joan Hartley -Senator

Amy Justice -Yale School of Public Health, VACS

Lisa Krumholz –for Harlan, Yale School of Medicine

Mark Masselli - Community Health Center

Matt McCooe -CT Innovations

Joe McGee - Commission on Economic Competitiveness

Polly Painter – SDO Policy

Tom Peters - UCONN

Wendy Sherry -CIGNA

Lisa Stump – SVP and CIO, YNHH, YSM

Bill Vallee -State Broadband Office