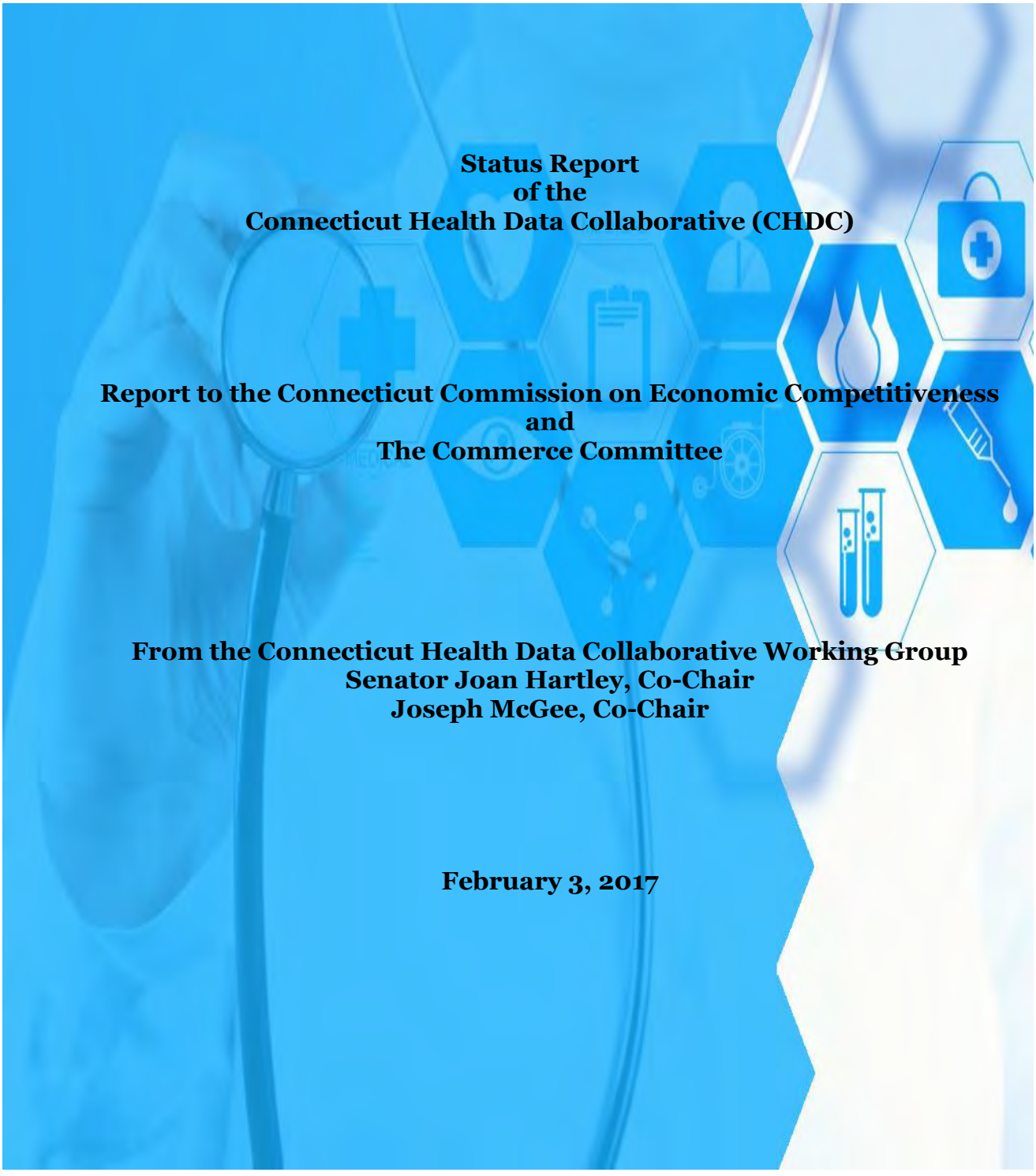

Status Report
of the
Connecticut Health Data Collaborative (CHDC)

Report to the Connecticut Commission on Economic Competitiveness
and
The Commerce Committee

From the Connecticut Health Data Collaborative Working Group
Senator Joan Hartley, Co-Chair
Joseph McGee, Co-Chair

February 3, 2017

Executive Summary

In 2015, a state economic competiveness diagnostic was performed and provided insights into Connecticut's economic strengths and challenges. **Key findings showed that we have great assets and strong economic drivers in research and development, bioscience and health data**.

In response to those key findings, the passage of Special Act 16-20 established the Connecticut Health Data Collaborative Working Group (CHDC). With the goal of creating stronger networks and partnerships among existing institutions, participant stakeholders convened from the fields of community health, healthcare, health insurance, research and development, education, data and technology, bioscience among others. They were charged with finding ways in which stakeholders can -- and should-- collaborate more effectively, rather than working independently of one another. After just four and half months of intense focus on synergies and relationship-building, new opportunities have been identified, new partnerships have formed, and audacious goals are being set to make Connecticut a national leader in the field of precision medicine and personalized health. The following summary serves as a status report of the work of the CHDC.

Thanks to the leadership of the group's committed stakeholders, a new vision for the development of the precision medicine and personalized health sector has emerged. The CHDC has identified four areas of collaboration to serve as guiding pillars, including:

1. **Research and development**
2. **Economic growth initiatives**
3. **Access, privacy, and security initiatives**
4. **Data of population health**

Connecticut would be one of the first in the nation to adopt a statewide initiative which would leverage our world class academic and research institutions, hub of insurance organizations, and a growing tech industry. Within each of these pillars listed below, the CHDC has identified goals that will put the state in a strong position to retain and attract talent, build an economic cluster around precision medicine and health data, and promote population health.

Pillar One: Research and Development for Precision Medicine and Personalized Health

1. Support foundational and translational research and development;
2. In partnership with Connecticut Innovations (CI) among others, facilitate and organize the procurement of CI Bioscience funds through **demonstration projects and clinical trials** supporting ventures in bioscience through competitive grants;
3. Establish The Connecticut Center for Genomic Medicine, which will be home to a Connecticut **Biobank**; adopt and recommend **standards and protocols** for acquiring, transferring and managing health data across the state.
4. Pursue research and development of the microbiome;
5. Formulate and implement a **comprehensive engagement plan** for genomic testing so that patients remain the focal point of precision medicine and personalized health.

Pillar Two: Economic Growth Initiatives

Establish and maintain an **Asset Inventory** across the state to identify CT organizations and companies working in bioscience, biopharma, biotech, genomics, clinomics, epigenomics, pharmacogenomics as well as the microbiome field and other related fields. The inventory will function as a **centralized information** base and help to:

1. Coordinate the use of precision medicine resources, and stimulate cross-sector collaborations among the state's scientists, clinicians, entrepreneurs and patient participants, enabling them to turn available large data sets and technical innovation into better health outcomes;
2. Serve as a leverage point for the economics of precision medicine in the state and beyond our borders;
3. Identify, facilitate, and build partnerships with state educational entities to assess and expand the necessary **education and workforce pipeline** for health informatics, health analytics, and genomic counseling programs ensuring we are preparing the workforce of the future to fill our requisite needs;
4. Promote **business development** through **competitions** that will incentivize firms or individuals located anywhere in the world to come into Connecticut; **retain talent** and **invite and recruit** experts in the fields of precision medicine and personalized health to work in Connecticut to build critical mass of talent.
5. **Cultivate entrepreneurial enterprises** that seek to improve precision medicine and personalized health, fostering innovation.

Pillar Three: Health Data Access, Privacy, and Security Initiatives

As health management is relying more and more on electronic record keeping and technology platforms, stakeholders will be charged with identifying best practices and supporting innovations that strengthen privacy and secure record-keeping, putting patients at the center of care. Though security will drive any initiative, identifying the most cost-effective means for managing health data will be key to achieving that end and must address three challenges:

1. Establishing **access and privacy standards** for the protection and safety of patient data;
2. Supporting the establishment and sustainability of the most cost-efficient and secure methods for data collection, transfer and management;

3. Promoting and seeking out data and technology initiatives that improve efficiency, safety, and protections for the health and health data sectors with particular focus on cybersecurity.

Pillar Four: Advancements in Health Data and Population Health

1. Promote efficient and innovative platforms for collecting data in order to understand the interplay between genetic, behavioral and environmental factors in the incidence of disease or illness. We know these types of data capture can lead to many positive outcomes, including:
2. Disease preventions, treatments, and cures, through: wellness management, disease detection, safety improvements, rehabilitation, and environmental exposures.
3. Innovations in collecting, managing and understanding health data

We've just begun to understand and positively influence how the social determinants of health impact overall health and well-being in relation to genomic data. The state has the potential to improve overall population health while investing in the solutions at the same time. Cultivating an economic environment that will attract and retain researchers and entrepreneurs to build on existing innovations will be a key to our success.

Conclusion

Today, new approaches to healthcare aim to deliver more effective, predictive and precise care to each individual. From prevention to diagnosis to treatment, each individual's experience will be different based on their genomic data in relationship to what is known about that person's unique characteristics, circumstances, and social determinants of health. Stakeholders
have addressed some of those critical relationships, but we are only at the beginning. There is much to be learned from the early adopters in other states to bridge current divides, fill gaps, and pursue unmet needs. The economic impact of building a cluster and critical mass around precision medicine will have strong and positive reverberations across the state.

Recommendations:

1. Establish a more formal collaborative to coordinate stakeholders in order to facilitate efforts, cultivate public-private partnerships and promote precision medicine and personalized health, including but not limited to:
    a. Determining best strategies to achieve the goals established based on the four pillars of collaboration and the resources for supporting those goals;
    b. Supporting grant applications for public, private and public/private partnerships
    c. Organizing a working group in order to improve existing metrics and synthesize measurements that better capture the relationship between state investments and economic outcomes including employment numbers and their multiplier effects;
    d. Taking steps to identify and address workforce gaps and workforce needs to fill the talent pipeline from entry-level to high skill level jobs needed for the future;
2. Pursue a state partnership with the California Initiative to Advance Precision Medicine (CIAPM).

Lessons from Early Adopters in Other States and Opportunities for Connecticut

In response to the work of some of the nation's early adopters, real opportunities for Connecticut have emerged. For example, expanding and building on current successes of our neighbors, encouraging innovation through competitions, and reaching out to underserved communities to address unmet potential are just a few of the many opportunities described below.

EXPANDING THE REGIONAL ECONOMIC SECTOR

New York and Massachusetts: New York Genome Center (NYGC), New England Precision Medicine Consortium

The New York Genome Center is a leading biomedical research and clinical care organization located in New York City. Founded in 2011 as a consortium of academic, medical and industry leaders across the globe, NYGC is a 501(c)(3) charity that focuses on translating genomic research into clinical solutions for serious disease.
Massachusetts General Hospital (MGH), Brigham and Women's Hospital, and Boston University School of Medicine, along with Boston Medical Center (BMC) — together they are the New England Precision Medicine Consortium and members of the New England Council, "a leading voice for the region's business community."[1] The Consortium was chosen to implement the Precision Medicine Initiative (PMI) Cohort Program. The Consortium, will receive $5.5 million in initial funding from NIH to find volunteers for the program, collect their health information, and provide input on the development of plans.

CT Opportunity: Using the NYGC and New England Precision Medicine Consortium as models, the Connecticut may benefit from the important work going on in our neighboring states. There has been a real spillover and multiplier effect as work has expanded into Connecticut in bioscience, biotech, biopharma and other technology and entrepreneurial enterprises. The state is a prime location for businesses and healthcare organizations that want to access the benefits of Connecticut, New York and Boston but are increasingly being priced out of the markets of our neighbors.

[1] https://newenglandcouncil.com/blog-post/boston-area-hospitals-chosen-for-nih-precision-medicine-initiative/

LEVERAGING COMPETITIONS

Indiana:
Indiana Grand Challenges Program

Indiana University School of Medicine offered a funding challenge to its faculty members: $300 million over five years to address some of the most urgent challenges facing Indiana and the world. Winners included transformative, innovative and interdisciplinary research proposals and precision medicine initiatives were at the forefront of the chosen proposals. In addition to substantial financial support, the IU Grand Challenges Program also provides up to 30 new faculty positions, as well as support for faculty startup needs, graduate students, postdoctoral fellows, equipment and facilities for each funded proposal.[2]

CT Opportunities:

- Much like the competition in Indiana, the state could offer investments for competitive grants using precision medicine and personalized health initiatives. In addition, competitions like Connecticut Innovations' Venture Clash could serve to attract early and second stage businesses from all over the world in the fields of precision medicine and personalized health. Winners would be required to establish their headquarters and build their businesses in the state, preferably in conjunction with Innovation districts.
- With increased attention to expand innovation districts leveraging the passage of "SB1" in 2015, particular focus could be paid to life sciences and precision medicine in both New Haven (in relation to Yale) and Farmington and Hartford (in relation to UCONN) among others. An organized collaborative could provide leverage for those innovation districts to develop incubator spaces, attract and retain talent in the state, and build a robust community in precision medicine, personalized health, and more in the life sciences.
- Any grant winners and "almost winners" from NIH or SBIR where much of the research labor has already been completed could also be supported with state matching grants and/or private investments. Many of these qualified proposals deserve to be revisited and improved with a modicum of financial support. An organized collaborative could act as a broker for venture capitalists to invest in ideas with the most potential.

ADDRESSING HEALTH DISPARITIES

Pennsylvania: Geisinger's MyCode Initiative®

Geisinger Health System already has more than 120,000 participants enrolled in its MyCode Community Health Initiative, a precision medicine project that includes a system-wide biobank designed to store blood and other samples used by researchers to help develop optimal treatments tailored to the individual needs of Geisinger patients. Geisinger's status as a PMI Cohort Program enrollment center means patients already participating in the MyCode Community Health Initiative

[2] http://news.medicine.iu.edu/releases/2016/01/grand-challenges-precision-medicine.shtml Jan 2016

will now have the opportunity to enroll in the national precision medicine program.[3] However, more than 95 percent of the populaton served by MyCode® is of White European ancestry; thus, limiting its scope and precluding opportunties for understanding health disparities.[4]

CT Opportunity: This limitation paves the way for Connecticut to finds ways to bridge the health disparities gap, a priority for our state as well as the national intiative. An organized collaborative could help focus partnerships that address disparities. For example, an existing partnership between Cigna and Trinity Health focusing on Hartford's North End community with 10,000 lives may allow a pilot program for genomic mapping for certain precision medicine initiatives to take hold.

PREVENTION AND WELLNESS FOR POPULATION HEALTH

Other organizations in various states across the country previously listed have applied for funding through the PMI Cohort program, but many opportunities exist as discussed at the CHDC:

CT Opportunities: An organized collaborative could pursue diverse pilot programs raised for consideration, including:

- Connecticut State Employees: initiate pilot programs for groups of employees to participate in genomic testing paired with genomic counseling with the goal to identify individuals with a predisposition to certain diseases. The pilot programs could engage both labor and management to improve the level of participation.
- Outreach to stakeholder organizations participating in the CHDC and a more formal collaboration with entities who are self-insured, ERISA companies, including: Anthem, Cigna, Aetna, Trinity Health, Yale School of Mediicne and Yale New Haven Hospital System, UCONN, and UCONN Health Center among others. Volunteers would participate in genomic testing as a covered benefit with any potential subsidy to be determined.

POLYPHARMACY AND PHARMACOGENOMICS

Indiana: Indiana Institute for Personalized Medicine

INGenious (Indiana Genomics Implementation: An Opportunity for the Under Served) study, is part of an NIH pilot program called IGNITE that has received more than $11 million in funding. The two-year study will enroll 6,000 patients, with 2,000 enrolled in the pharmacogenetic testing. The remaining 4,000 will be a control set that will be monitored, but not genetically tested. It will review whether the genetic analysis of a patient with hypertension, diabetes or heart disease helps

[3] http://www.prnewswire.com/news-releases/geisinger-selected-to-join-the-national-precision-medicine-initiative-300344215.html

[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4981567/#SD1

choose the better medication – and lead to better health. The study will also target 33 drugs -ranging from statins to psychiatric drugs – to see if there's a significant association with reducing hospital and outpatient costs over the course of a year.[5]

CT Opportunity: A recent proposal for a Statewide Patient Safety Initiative to expand the CT Prescription Monitoring and Reporting System (CPMRS) mirrors some of what IGNITE addresses. With a potential expansion of the CPMRS to include all prescription fills, invitations could be made to patients who may benefit not only from maintaining a more accurate record of their drug treatments, but also from the potential of genomic testing, ultimately improving the accuracy and appropriateness of drug treatments, saving millions in healthcare spend.

MANAGING PATIENT HEALTH DATA

Arizona|Florida|Minnesota: MAYO Center for Individualized Medicine (CIM)
California and Regional: Kaiser Permanente HealthConnect®

CIM is a "transformational" center with clinical, research and education responsibilities and its goal is to promote rapid translation of research into personalized clinical care and to create genomic medicine mechanisms that are instantly diffusible and applicable across Mayo Clinic's multiple, geographically dispersed campuses. Kaiser has also been at the cutting edge of electronic health record management using the EPIC platform that facilitates interoperability.

CT Opportunity: With their multi-state approach and their capability for interoperable electronic health records, both Mayo and Kaiser have been able to facilitate the access, transference, and storage of health records to great benefit to their patients. With many of Connecticut healthcare providers relying on the EPIC platform for electronic health records, the state is better-positioned to improve the movement, storage, and management of genomic data more quickly and efficiently than other health systems once the data has been generated. Not without its challenges, however, EPIC will require even more innovative solutions in the management of health data with the inevitable addition of genomic data into the patient record. There are also current innovations taking place that could be expanded in a pilot program partnership, using patient-centered data platforms, allowing for patients to be the holders of their own data, at the center of their own care management.

BUILDING THE WORKFORCE PIPELINE

Vanderbilt, Penn Medicine, Brandeis, **Cornell**, and a host of other private and public universities across the country now offer degrees in health informatics and health information technology. Related fields of genomic counseling and cybersecurity will also play a large part in the successful workforce pipeline of the

[5] http://medcitynews.com/2015/05/precision-medicine-save-money-indiana/

future in precision medicine and personalized health. Currently, the demand outnumbers the graduates. The need for education and training in health informatics, data analytics, and genomic counseling will be great, as precision medicine and personalized health become part of our daily health maintenance and record-keeping.

CT Opportunity: With our world-renowned universities and colleges across the state, it is incumbent upon our institutions of higher education to meet the demand of our future needs. UCONN's small but critically important program for genomic counseling, The University of St. Joseph's Health Informatics certificate and a potential partnership between UConn and Yale University to develop a program in health informatics holds much promise. Establishing a working group of industry leaders, community health organizations and institutions of higher education to provide guidance on charting a course to meet emerging workforce demands would be very beneficial.

STATE to STATE PARTNERSHIP

California: California Initiative to Advance Precision Medicine (CIAPM)

With leadership from Governor Brown, the launch of the California Initiative to Advance Precision Medicine (CIAPM) took place in 2015. Hosted by UC San Francisco, this partnership between the state, the University of California, and other public and private entities seeks to build the infrastructure and assemble the resources necessary to advance precision medicine-oriented data, tools and applications. In addition to developing demonstration projects, CIAPM is conducting an inventory of California's vast technological and medical resources that make precision medicine possible. The California 2016 Budget Act included approximately $10 million for the CIAPM.[6]

CT Opportunity: California has been a national leader in its commitment to the precison medicine initiative. UC Health and UCSF host CIAPM with the Governor's Office of Planning and Research, though they are currently undergoing an evaluation of the existing governing structure. Governor Brown's office has reached out to the CHDC in order to develop a "sister state-wide partnership" to share best practices. Formalizing this partnership would make it the first of its kind in the nation.

We are still on the cutting edge of what is possible. By leveraging existing assets and pursuing a bold new vision, the state is poised to live up to its revolutionary reputation and become a leader and innovation center once again in the burgeoning fields of precision medicine and personalized health.

[6] https://www.gov.ca.gov/news.php?id=19603

Connecticut Health Data Collaborative Participant List

Organization	Name	Title
CT Technology Center	Bruce Carlson	President and CEO
Level 3	Carl Bonitz, Jr.	General Manager
Anthem	Christine Cappiello	Government Affairs
Aetna	Chere Parton	Chief Operating Officer of iTriage
CCAT	Daniel Salazar	Director of IT Services
Trinity Health	Dr. Amit Mody	SVP, Growth, Strategy, & Innovation
VA and Yale University	Dr. Amy Justice	Professor of Medicine (General Medicine) and of Public Health (Health Policy
Yale School of Medicine	Dr. Harlan Krumholz	Director of the Yale New Haven Center for Outcomes Research and Evaluation
Mount Sinai Genetic Testing Lab	Todd Arnold, PhD	Managing Director
UCONN Health	Dr. Tom Agresta	Director of Medical Informatics of Family Medicine
UConn Engineering	Tom Peters, PhD	Professor
Office of the State Comptroller	Tom Woodruff, PhD	Director, Healthcare Policy & Benefit Services Division
Mount Sinai Genetic Testing Lab	William Loging, PhD	Associate Professor of Genetics and Director of Pharmceutical Alliances
Office of Consumer Counsel	Elin Katz	CT Consumer Counsel
CT Center for Advanced Technology CCAT	Elliot Ginsberg	President and Chief Executive Officer
CT Hospital Association	Jim Iacobellis	Senior Vice President of Government and Regulatory

Commerce Committee	Joan Hartley	State Senator
Commission on EC	Joe McGee	Co-Chair
Yale New Haven	Dr. Lisa Stump	Sr. Vice President & Chief Information Officer
Cigna	Deb Hutton	Government Affairs
Community Health Center	Dr. Mark Masselli	Founder
Connecticut Innovations	Matt McCooe	Chief Executive Officer
Dossia Service Corp.	Michael J. Critelli	President and CEO
Frontier	Mike Cicchetti	Director, Government and External Affairs
The Jackson Lab	Mike Hyde	Vice President for External Affairs and Strategic Partnerships
Anthem	Dr. Peter Bowers	Anthem Medical Director
SDO Policy	Polly Painter	Policy Liaison, Commerce Committee
Commerce Committee	Scott Frantz	State Senator
Health Equity Solutions	Takesha Dwan Everette, PhD	Executive Director
Office of The Lt. Governor	Vicki Veltri	Chief Health Policy Advisor
Cigna	Wendy Sherry	COO, NE Region
UCONN Health	Dr. Marc Lalande	Professor and Chair, Genetics and Genome Sciences
Office of Consumer Counsel	William Vallee, Jr.	CT Broadband Policy Coordinator
CT State Innovation Model (SIM)	Mark *C.* Schaefer*, PhD*	Director
Connecticut State Medical Society	Ken Ferucci	VP Public Policy and Government Affairs