

[9] Draft Proposal for the “CT **Initiative for Personalized Health**” [need to choose]

What is personalized health (also known as precision and/or personalized medicine) This transformational approach to health and healthcare aims 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 **history**, characteristics, circumstances, and social determinants of health.

What are the benefits of precision health? Many observers feel that precision medicine is the innovation that will allow health information technology to leverage advances in genomics, and biomedical discoveries, while accelerating research and protecting patient privacy.¹ Current approaches to medicine and health are based on a “one size fits all” model relying on trial and error within a general population. Personalized medicine is individualized and provides “the right treatment for the right person at the right time.”² Benefits include the following:

- Ability to diagnose disease more accurately
- Select optimal therapies and target medicines and dosages more precisely
- Increase safety, reduce adverse drug reactions
- Detect onset of disease at the earliest moments
- Shift emphasis in medicine from reaction to prevention and wellness
- Increase the efficiency of the health system by improving quality, accessibility and affordability

How will personalized healthcare change the role of the health care providers, payers and pharma?

- ~~Providers will act as care manager, rather than repository of medical knowledge—“less artist, more scientist.”~~
- Providers will have greater reliance on health information technology (HIT) for decision support
- Improved care will result through use of **de-identified and well-managed** patient data
- Care will be highly networked, team-based and patient-centered
- New ethical and legal issues/quandaries will surface
- A new analysis from the Personalized Medicine Coalition (PMC) documents an upward trend in the number of personalized medicine approvals at FDA, with personalized medicines accounting for more than **1 in 4 novel new drugs** (NNDs) approved in 2015. The analysis, titled [2015 Progress Report: Personalized Medicine at FDA](#), lists the 13 personalized medicines approved as NNDs in 2015, which represent **28 percent** of the 45 NNDs the agency approved overall.³

¹ Health Catalyst <http://www.slideshare.net/healthcatalyst1/the-real-opportunity-of-precision-medicine-and-how-to-not-miss-out> David K. Crockett, Ph.D. is the Senior Director of Research and Predictive Analytics.

² [Edward Abrahams](#), PhD, President of the Personalized Medicine Coalition

³ http://www.personalizedmedicinecoalition.org/News/Press_Releases/More_Than_1_in_4_Novel_New_Drugs_Approved_by_FDA_in_2015_are_Personalized_Medicines#sthash.2zzLAHki.dpuf

- Payers will place a greater emphasis on clinical validity and utility of diagnostic tests. There will be an increased need to demonstrate cost efficiencies. There will be increased pressure to change the paradigm towards ~~personalized medicine and~~ value-based care.

Establishing the Connecticut Center for **Personalized Health**

Background: With the passage of SA 16-20, the Commission on Economic Competitiveness formed and has been convening members of the Connecticut Health Data Collaborative since June 2016. Propelled by industry leaders including insurance companies, institutions of higher education, bioscience organizations, hospital systems, healthcare providers, technology experts and companies, state agency leaders, and others who have had a keen and vested interest in the field of precision health, the collaborative has developed a proposal to formally establish the Connecticut Center for Precision Health.

Vision: to fulfill the promise of patient-centered care through precision medicine.

Mission: Partners collaboratively work to educate, find cures, reduce the incidence of disease and improve the health of diverse populations through the use of genomic, social, behavioral, environmental, and clinical data.

Goals: to lay the groundwork for innovation, the Connecticut Center for Personalized Health will pursue five main goals: (1) to expand access to patient data while maintaining safety and security protocols for better treatments and care that put patients at the center of their health and healthcare (2) to assemble an extensive inventory of precision medicine assets in Connecticut, (3) to support demonstration projects that have the potential for tangible benefits to patients and overall population health, (4) to build the necessary education pipeline to fill the workforce needs necessary to support a precision health sector, and (5) to explore partnerships with the state of California **and others in a collaborative effort** to establish best practices in precision health.

Strategies: The overarching organizing body will foster collaborations in a multitude of ways, including:

1. Formulate and implement a **comprehensive engagement plan** so that patients remain the focal point of personalized health to ensure they understand and can think critically about their own choices, including: 360 degree feedback loops that utilize surveys, focus groups, targeted electronic, digital and social media platforms among others.
2. 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**, including: research projects and clinical studies, databases, and analysis platforms. **Supply chain entities will also be included.** The inventory will:
 - Function as a **centralized information** base;
 - 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.

- Catalyze the economics of precision medicine in the state and beyond our borders.
- 3. Partner with state educational entities to assess, identify and help to build the necessary **education pipeline** for health informatics, health analytics, and genomic counseling programs ensuring we are preparing the workforce of the future.
- 4. Expand the state prescription monitoring program ([CPMRS](#)) database to include all prescription fills.
- 5. With Yale's leadership and in collaboration with partners from the Connecticut Health Data Collaborative (including YNHHS, Yale University, UCONN, **Community Health Center**, UCHS, JAX, Mount Sinai, Aetna, Anthem, Cigna, professional medical **and healthcare associations and relevant state partners** among others), **apply for an NIH grant out of the Precision Medicine Initiative. Funds will help to:**
 - **Establish the Connecticut Biobank** – an open access database for patient de-identified genome data and health history; identifiable data possible with patient permission;
 - **Build the database** by identifying strategies to identify **participants who volunteer** for genomic clinical trials from: 1) the expanded CPMRS database, and 2) ERISA companies and CT State Employee insurers which will offer genomic profile **as part of prevention benefit pilot program** 3) other interested patients ensuring a diverse pool reflecting our overall population.
 - Partners in the CT Biobank will establish **standards and protocols** for collection, analysis, and storage of genomic data (in coordination with NIH) and other appropriate and relevant data.
- 6. Partners will establish **access and privacy standards** for the protection and safety of patient data (in coordination with NIH).
- 7. Establish the **CT Precision Health Code of Ethics Advisory Board** who will seek to determine and advise collaborators of best practices in precision health.
- 8. In partnership with Connecticut Innovations, organize the procurement of CI Bioscience funds through **Demonstration Projects** supporting ventures in bioscience through competitive grants.
- 9. **Develop comprehensive plan including education, outreach, enrollment and support strategies** to elicit a representative and diverse population base, ensuring that patients remain at the center of their own health and care on a longitudinal basis, ensuring continued sampling of and access to progressively advanced treatments as they become available over the lifetime of the patients.
- 10. **Develop and support relevant legislation** including but not limited to: prohibiting any and all discrimination (including life insurance) based on any genomic mapping findings and results.
- 11. **Cultivate entrepreneurial enterprises** that seek to improve personalized health.
- 12. **Support the establishment and sustainability of the CT State Health Data Network.**

Funding mechanisms: The Connecticut Center for Precision Medicine will, as a collaborative, or as an entity that provides institutional support for its members, apply for NIH grant(s), state investment grants from Connecticut Innovations, including CT Next and the CT Bioscience Fund; and other public/private investments.

Source: Personalized Medicine Coalition

