

# HERO CMO/CHO SUMMIT PROCEEDINGS

A **20/20**

**Vision for Precision Population Health.**

Precision Population Health and Personalized Medicine,  
Kindred Spirits or Strange Bedfellows?

**A Think Tank for Chief Medical Officers and Chief Health Officers  
Held February 24th in Sonesta, Fort Lauderdale, Florida**



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# PROGRAM SUMMARY

This CMO/CHO Summit examined both personalized medicine and precision population health and challenged participants to consider whether trends in personalized medicine should be affecting company sponsored worksite health and well-being initiatives. The promise of personalized medicine relates to innovations in data access and genomics that better provide for tailoring the right treatment to the right person at the right time. Could the same tech abetted opportunities for more precise and tailored interventions be occurring in population health, particularly for workplace-based health promotion? Given genomics and precision medicine are broad disciplines, we urged our summit faculty to focus on the unique role employers can play in shaping health policies relating to precision population health. Even though this summit was designed to envision a new era in worksite wellness that encompasses genomics, it remains that worksite health and well-being initiatives to date have not been highly personalized. HERO Scorecard data shows, for example, that a minority of companies base their initiatives on written strategic plans, much less on highly customized population level data analysis. Accordingly, our opening keynote presentation was delivered by Dr. Muin Khoury, the Founder and Director, Office of Genomics and Precision Public Health at the Centers for Disease Control and Prevention. Dr. Khoury's topic was "Beyond Public Health Genomics: Can Big Data and Predictive Analytics Deliver

Precision Public Health?" You can find key readings from Dr. Khoury in the reading list at the end of these proceedings, and he served as a reactor panelist in summit session one (session recordings below) relating to how employers can shape the direction of precision population health.

As the summit planning committee discussed the agenda and recruited faculty who could address employers' concerns relating to collecting and acting on genomics data at work, debates ensued about how best to put precision population health management into the context of supporting employee health and ensuring privacy while containing health care costs. Committee members agreed that this summit should raise key questions even though clear answers may not yet be attainable. Accordingly, faculty were asked to present on their specialty areas of research and policy and were also asked to reflect on questions such as the following. How important is the role of genetic screening and pharmacogenetics compared to the role of data relating to social determinants of health (SDoH), employee ZIP codes, or other demographic and socioeconomic status data? Considering "genetic exceptionalism," do you agree genetics data collection should benefit from new privacy guidelines and protocols? Or, are HIPAA and GINA enough? And what role should employees play in the acceptability of data collection? Should CMOs and the employees they support care

about the difference between traditional genetics (how genes are transferred) and epigenetics (metadata about how genes are expressed)? And with respect to the low rates of customized strategies informed by population health data, what difference should genetic confirmation of health conditions make in population level health promotion planning?

Summit presentations are available on HERO's YouTube channel and are summarized below along with many key concepts, studies, and policy recommendations that will inform and challenge employer leadership in the months and years ahead. These proceedings summaries also draw from journal editorials written by program director Dr. Paul Terry before and after the summit.<sup>1,2</sup> The presentations are:

**Session One** on HERO's YouTube Channel: *"How employer leadership can shape precision population health."*

**Session Two** on HERO's YouTube Channel: *"Deterministic (a gene centric approach) vs. Probabilistic (preventing common conditions): How to make these approaches complementary, not competing."*

**Session Three** on HERO's YouTube Channel: *"Reconciling Precision Medicine with Precision Population Health: The role of big data, advanced analytics and artificial intelligence."*

# CMO/CHO SUMMIT FACULTY AND PROGRAM DIRECTORS



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**Michael Doney**, MD, MPH, MS, Head of Medical Affairs, Color Genetic Screening Study



**Eric Fung**, MD, PhD, Senior Medical Director, Grail, Inc.



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**Dexter Shurney**, MD, HERO Board Member and CMO, Zipongo

**Mark Cunningham-Hill**, MD, Medical Director, Northeast Business Group on Health

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# SUMMIT PRESENTATION ABSTRACTS AND CONTENT SUMMARIES FOR A 20/20 VISION FOR PRECISION POPULATION HEALTH.

*Precision Population Health and Personalized Medicine, Kindred Spirits or Strange Bedfellows?*

CMOs and CHOs have responsibilities that include interactions with the healthcare systems alongside their work with an employee population. Where personalized medicine focuses on bringing greater precision to individual treatments, the genetics revolution also invites questions about how genetics testing and genetics reference panels and databases can be applied in a workplace wellness context. The terms “precision population health,”<sup>3</sup> “precision health,”<sup>4</sup> or “wellness genomics”<sup>5</sup> all reflect fresh thinking about how best to put genetics information to work on behalf of improving health at the population level. Ever since the Human Genome Project<sup>6</sup>, we have been experiencing what many describe as the “genetic revolution.”<sup>7</sup> Millions die worldwide from genetic diseases such as sickle cell anemia, but researchers are experimenting with modified stem cells and enthusing about the real possibility that they are within reach of a cure. The prospect that modifying just one mutated letter in a genomic sequence could relieve millions of a disease would seem to hold nothing but positive promise and has spawned a growing discipline called “personalized medicine” (PM).

As the emergent debates about the best ways to exploit the genetics revolution indicate, CMOs and CHOs are at a juncture where we need to strike the right balance in the use of genomics that advances both individual and

social responsibility for health. Related to this, considerations of genetic screening as an assessment tool too often comes without a concomitant plan for genomics-inspired educational or policy interventions. During this summit, we discussed how recent studies concluding that worksite wellness didn’t work have been based on intervention designs that reinforced long-standing concern that employers routinely over-assess and under-intervene.<sup>8</sup> The idea that DNA screening needs special protections beyond HIPAA or GINA regulations is referred to as “genetic exceptionalism.” Though your medical record contains highly personal information, the argument goes that genetic information is such an immutable, powerful, unique identifier that it will demand unique protections. Learning that the differences in your DNA link you to a lower than average level of omega-3 fatty acids is a perturbation most will readily cope with. But learning you have non-curable Huntington’s disease engenders the kind of discrimination or stigma associated with serious mental illnesses. Indeed, advocates for genetic exceptionalism propose that, at least, genetic information has the kind of limited access afforded mental illness records.<sup>9</sup>

The three learning sessions summarized below challenged faculty and summit attendees to consider how employers can invest in genomic screening in a way that provides new

opportunities to prevent disease while ensuring privacy protections. We asked faculty to describe how to proactively connect screening data with robust interventions and ongoing program evaluation and population level results reporting.

In session one, experts in population health, preventive medicine, oncology and pharmacogenetics shared their views on genetic exceptionalism, trust, data privacy and security.

**Session One** on HERO’s YouTube Channel: *“How employer leadership can shape precision population health.”*

Facilitator: William Kassler, MD, MPH, FACP, CMO, Government Health & Human Services; Deputy Chief Health Officer, IBM Watson Health Faculty:

- Muin J. Khoury, MD, PhD, Founder and Director, Office of Genomics and Precision Public Health, CDC
- Howard McLeod, PharmD, Medical Director, Precision Medicine, Geriatric Oncology Consortium; Professor, University of South Florida Taneja College of Pharmacy
- Patricia A. Deverka, MD, MS, Chief Science Officer, Innovation Value Initiative

Dr. Howard McLeod's presentation emphasized the utility and limits of probabilistic data in deciding about the need for interventions. (His PowerPoint slides are not available, but his oral narrative offers vivid details.) Dr. McLeod offered specific examples of how the evolution of pharmaceutical sciences affords ever more specificity about the kinds and doses of medicines as they impact conditions differentially according to race and other demographic data. He described how employers can better tailor their formularies to be more responsive to their employee population's genomic profile and other health attributes. Dr. Patricia Deverka detailed policy issues she has been researching relative to use of genomic data at the workplace, and she offered "conservative guidance" for CMOs/CHOs considering integrating genetics in worksite wellness. As seen in her PowerPoint slides, her recommendations included assessing employee interests and concerns, maintaining information firewalls preventing employer access to genetic testing results, choosing a reputable genetic screening vendor, and ensuring voluntariness of any genetic screening component. Dr. Khoury offered reactions to the presentations and closed this first session with a call to action for employers interested in genetic testing where, in addition to sharing best practices concerning effective screening and monitoring/ they also avail themselves as partners in scientific research.

See the recommended readings provided below for additional information about how personalized medicine can best strike a balance between pharmacogenetics treatment tailoring and the prevention aspects of improving population health. For example,

Vogenberg and colleagues suggest "a profile of a patient's gene variations can guide the selection of drugs or treatment protocols that minimize harmful side effects or ensure more successful outcomes. Precision medicine can also indicate an individual's susceptibility to certain diseases before they become manifest, allowing physicians and patients to design a plan for monitoring and prevention."<sup>10</sup> Borrowing from this definition, precision medicine is often simply referred to as 'the right treatment at the right time for the right person.' With 7000 genetic diseases with known mutations, the genetics revolution has only just begun. And the word revolution seems especially apt given the movement is already being met with fierce resistance. At the same time that countless patients are desperately praying for more funding for stem cell research, legal and ethical issues about "playing God" are being debated.

Following this summit's proceedings, summit program director Paul Terry proposed and published a definition for "precision health promotion." He defined precision health promotion as "the personalized design of lived experiences that foster improved health and well-being for individuals within the context of their families, organizations and communities." A "lived experience" is generally thought of as those moments when we are so engaged in our environments that the moment, the experience, shapes our thinking and behavior and that of those around us. Joining together the disciplines of phenomenology and health education, lived experiences are those learning experiences or place-based, environmentally informed experiences that fuel our understanding and influence our attitudes and beliefs. Precision health promotion

suggests that genetics information could be as influential in health improvement as is culture or education. Some who have had the good fortune of experiencing a full immersion into another culture know how life-changing that can be. So too would be the intentional design of organizations and communities grounded in a culture of health and responsive to individual differences. Precision health promotion, then, to borrow from the common definition for personalized care, is when the right lived experience is designed with and for the right person at the right time. It's an experience that fully considers how changes in their organizations, families, or communities can foster or diminish their personal health and well-being. Research will be needed to determine whether learning experiences spawned by new genetic information will prove to be as influential as other lived experiences. Nevertheless, few doubt that precisely personalized learnings about the influence of our families and ancestors on our biological makeup can offer compelling new ways to motivate healthy behavior.

**Session Two** on HERO's YouTube Channel: "*Deterministic (a gene centric approach) vs. Probabilistic (preventing common conditions): How to make these approaches complementary, not competing.*"

Facilitator: Wayne Burton, MD, Clinical Associate Professor, Feinberg School of Medicine, Northwestern University; Consultant, Strategic Advisor; Former CMO, American Express Faculty:

- Josh Peterson, MD, MPH, FACMI, Associate Professor of Biomedical Informatics and

Medicine, School of Medicine at Vanderbilt University

- Eric Fung, MD, PhD, Senior Medical Director, Grail, Inc.
- Michael Doney, MD, MPH, MS, Head of Medical Affairs, Color Genetic Screening Study
- Meghan Patton, MS, SPHR, SHRM-SCP, FABC, Senior Vice President, Human Resources and Associate Chief Human Resources Officer, Thomas Jefferson University and Jefferson Health

In this session, faculty presented lectures on how to balance biology, lifestyle, and environment in population health strategy planning. Dr. Josh Peterson discussed the “eMerge 3” study he co-leads at Vanderbilt and the near term opportunities, using genetic counselors, to intervene on conditions such as familial hypercholesterolemia. Depending on who is sequenced, Peterson estimates 10-40% could benefit from tailored prescriptions and personalized screenings. Dr. Eric Fung discussed “universal cancer screening” and contrasted this approach with select screenings such as colonoscopies or mammography. He anticipates we will move from our current focus on ‘who to screen’ to a broader capability relating to screening for many different kinds of cancers simultaneously. He also detailed screening testing sensitivity improvements and the high detection rates for cancers across multiple cancer stages. Dr. Michael Doney described a “responsible approach to population genetics,” one that emphasizes the return of results and the “grounding of genetic results in an overall risk assessment” that considers familial and lifestyle related components of risk. Doney explained an approach where results are “gated” such that participants need to review results with a genetics

counselor. Counselor services are also offered to the participant’s healthcare team. Meghan Patton, Senior Vice President of Human Resources at Jefferson Health, described the genetic testing at her organization. Her recommendations for an effective rollout include strong privacy and security protections, a consensus based approach to clinical rigor and actionability, and a seamless experience with rapid results to tested individuals.

The planning committee asked the faculty for this session to address how the benefits of individual screening findings outweigh the hazards of keeping data private and reduce attendant concerns about disease discrimination. This session also explored what role employees play in the acceptability of data collection. We also asked these experts to share their views on whether genetics information will have more transformative impact on lifestyles and behavior changes than current screening and education approaches. In reviewing the arguments for how, if and when to apply genetics screening, competing views emerge. Some voice concerns that the rapid growth of personalized medicine will shift investments back toward individual fixes rather than societal level solutions. The worry that personalized medicine is medical-model thinking warmed-over harkens to a deterministic view where faulty genes are like broken bones that need repairing. This philosophy contrasts with a probabilistic view that genetics information should instead be used to help us do the greatest good for the greatest number. That is, very few would benefit individually from routine genetic screening, but information gleaned from routine screenings of newborns, for example, could greatly benefit at-risk populations.

An alternative view invites deliberation about how precision medicine and precision population health could be complementary fields with genomics-abetted big data serving as a common driver of innovations in both disciplines. This view invites a convergence of biological and social sciences where genetics databases and artificial intelligence are new tools to be put to work in resolving social determinants of health alongside preventing and resolving genetic diseases and intractable medical conditions.

**Session Three** on HERO’s YouTube Channel: *“Reconciling Precision Medicine with Precision Population Health: The role of big data, advanced analytics and artificial intelligence.”*

- William Kassler, MD, MPH, FACP, CMO, Government Health & Human Services; Deputy Chief Health Officer, IBM Watson Health

For this closing session and the attendant group discussion, the summit planning committee invited Dr. Bill Kassler to describe how precision medicine, particularly genomics, is informing population level data collection and strategic planning for population health at your organization. Dr. Kassler described the deep learning (a branch of machine learning) that can occur from a variety of data types. Kassler discussed how the exponential growth in data and how improved data integration and harmonization are informing human insights and improving decision support.

When genomic databases are conjoined with other epidemiological and social determinants of

health-related databases, such could create a vast opportunity to build the right health promotion initiatives, interventions, and ecosystem reforms at the right time for the right communities. A seminal definition of health promotion is “any combination of learning experiences designed to facilitate voluntary actions conducive to health.”<sup>11</sup> It is a definition from a leading textbook on health program planning for a field that has traversed from lifestyle medicine to wellness to achieving well-being and building cultures of health. In building a consensus definition, the initial use of the words “behaviors conducive to health” were replaced with “actions conducive to health.” They recognized the word “behaviors” was too narrow for a definition intended to engender a socio-ecological model sensibility. Using “actions” in the definition was more inclusive of the policies and environmental changes needed to affect population level, not just individual level, health improvements.<sup>12</sup> These trends in the health promotion discipline underscore why Kassler’s closing lecture related to social determinants of health.

Genetics testing will come to play a vital role in precision health promotion, but per Doney’s advocacy, education needs to be intentionally imbedded alongside other precision-enabling

variables like social determinants, health education, and environmental supports. Designing a social utopia where lived experiences are steeped in happiness, health, and well-being has been the quest of philosophers, social scientists, and community leaders for ages. Precision health promotion will not resolve nature versus nurture debates but, rather, aims to be informed by the best of both. The popularity of consumer DNA testing services indicates the health promotion landscape will be changing fast with more employers offering DNA testing as an employee health benefit.

The diagnostic nuances and ethical dilemmas that genetic testing will trigger will likely be debated for years to come. Some already argue that genetic exceptionalism is an overwrought concept and that the utility and uniqueness of genetic information is why clinicians need ready access to it just as they would other clinically important data.<sup>13</sup> Whether genetic exceptionalism is warranted isn’t a meaningful debate for the many who simply want to experience the big reveal about unforetold leaves on their family tree. And though having our blood drawn in the context of a workplace wellness screening has been accompanied by healthy debate about assuring health-related non-discrimination and

policies aimed at protecting employee privacy, worksite health screenings are generally popular and commonplace.<sup>14</sup> That is why data privacy was a central feature of a guidance paper HERO facilitated and published that emphasized the critical nature of privacy protections for worksite wellness as they relate to the use of incentives, and effective delivery of wellness programs.<sup>15</sup> Faculty for this summit were uniformly aligned behind GINA protections where workplace-based DNA testing requires that genetic information made available to employers be de-identified and aggregated, that employees provide voluntary consent in writing, and that only authorized healthcare providers have access to individually identifiable data.<sup>16</sup>

Throughout the day, we asked summit participants how community data, (i.e., income levels, violence rates, literacy, graduation rates, housing accessibility, food security) would affect a precision approach to population health management. Group discussions indicated easy consensus per the idea that genetic screening, technology and big data management need to play a more influential role in addressing social determinants of health.





# SUMMIT PLANNING COMMITTEE MEMBERS

Chair: Fikry Isaac, MD, WellWorld Consulting, Former CMO, J&J

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Karen Moseley, HERO President

Paul E. Terry, PhD, HERO Senior Fellow

## RECOMMENDED READINGS FROM CMO/CHO SUMMIT FACULTY AND OTHER EXPERTS

Muin J. Khoury, MD, PhD (Think Tank faculty). Michael F. Iademarco, MD, MPH, William T. Riley, PhD, **“Precision Public Health for the Era of Precision Medicine.”** Am J Prev Med 2016;50(3):398-401.

“Could the same technologies that propel precision medicine usher in a parallel era of ‘precision public health’ beyond treatment of sick individuals? If precision medicine is about providing the right treatment to the right patient at the right time, precision public health can be simply viewed as providing the right intervention to the right population at the right time.”

Muin J. Khoury and Sandro Galea. **“Precision Medicine and Population Health: Dealing With the Elephant in the Room.”** Posted August, 2017.

“We suggest that the debate can be resolved by shifting the focus from the health of individuals versus the health of populations to strengthening medicine and public health partnerships that address health problems and disparities and capitalize on emerging data and new technologies, without neglecting well-recognized foundational drivers that are root causes of population health.”

Muin J. Khoury, MD, PhD; Sandro Galea, MD, DrPH, **“Will Precision Medicine Improve Population Health?”** JAMA. 2016; 316(13):1357-1358.

Ron Zimmern, **“A commentary on Khoury & Galea Will Precision Medicine Improve Population Health.”** Aug. 2016.

**Are precision medicine and population health disparate disciplines?** “Dr. Muin Khoury, who is the director, the founding director, of the Office of Public Health Genomics at the CDC argues that the same technologies that propel personalized medicine such as genetics and big data could usher in a parallel era of what he calls precision public health.”

Ying-Chen Claire Hou, Hung-Chun Yu, Rick Martin, Elizabeth T. Cirulli, et. al. (M. Doney) **“Precision medicine integrating whole-genome sequencing, comprehensive metabolomics, and advanced imaging.”** National Academy of Science. Dec. 2019.

Paul Terry, PhD, (HERO Senior Fellow). **“Introducing “Precision Health Promotion: The Convergence of Genomics, Health Education, and Lived Experience.”** Editorial, The American Journal of Health Promotion, First Published January 29, 2020.

Paul Terry, PhD, **“Genetic Exceptionalism and Precision Health Promotion.”** Editorial, The American Journal of Health Promotion, First Published March 17, 2020.

Lyles, C.R., Lunn, M.R., Obedin-Maliver, J. et al. **“The new era of precision population health: insights for the All of Us Research Program and beyond.”** J Transl Med 16, 211 (2018).

“A limited number of underrepresented research participants can lead to inaccurate scientific conclusions, and increasing their numbers remains challenging in both clinical and genomics research [3]. .... The vision for community engagement in precision population health includes engaging participants in setting research priorities and ensuring that they receive research findings in ways that are accessible, meaningful, and foster education and implementation (in the spirit of community-based participatory research).”

Reenita Das. **“Drug Industry Bets Big On Precision Medicine: Five Trends Shaping Care Delivery.”** Forbes. Mar 8, 2017, The Death of One Size fits all.

“Precision medicine involving multi-level patient stratification holds the promise of optimizing the cost, time and success rate of pharma clinical trials by co-developing drug

medical prescription (Rx) and diagnostics (Dx) for future targeted therapies. ... Today, the drug development industry is betting heavily on precision medicine. Leading pharma/biopharma companies have nearly doubled their investment in personalized medicines in the last five years, and expect an additional 1/3 increase over the next five years.”

Ramya Ramaswami, Ronald Bayer, and Sandro Galea, **“Precision Medicine from a Public Health Perspective,”** Annual Review of Public Health, Vol. 39:153-168 (Volume publication date April 2018).

“More precise stratification of disease also introduces more financial burden and the potential for inefficiencies with little or no tangible clinical benefit. The challenge to population health is that using a disease process to improve individuals’ treatment may have limited utility for the improvement of overall population health. Creating several molecular classifications of one disease entity may subsequently fragment the management of these conditions, which may in turn impose significant strains on existing health services that deliver health care on the basis of organ systems rather than molecular subtypes.”

Michael F. Murray, et al, **“A Proposed Approach for Implementing Genomics-Based Screening Programs for Healthy Adults.”** National Academy of Science. Dec. 2018.

David A. Ahlquist, **“Universal cancer screening: revolutionary, rational, and realizable.”** Precision Oncology, V2: Oct. 2018.



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