A consensus on collaboration: reviewing the 15th Annual Personalized Medicine Conference at Harvard Medical School

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At the turn of the century, the emerging field of pharmacogenomics prompted sobering examinations of the efficiency and effectiveness of healthcare. An article published in 2001 in Trends in Molecular Medicine, for example, showed that treatments for six common diseases helped only 25–62% of the patients who receive them, depending on the disease in question [1].

By 2005, however, National Institutes of Health (MD, USA) Director Francis S Collins, who was then serving as the Director of the National Human Genome Research Institute (MD, USA), had published an op-ed in The Boston Globe suggesting that an emerging field called personalized medicine, defined by the use of diagnostic tests to help target prevention and treatment strategies to only those patients who will benefit from them, would inform more precise and effective interventions that address the root causes of devastating human diseases [2].

Recognizing the continued significance of these laudable goals for the future of medicine, the Personalized Medicine Coalition, which represents the perspectives of over 220 member institutions from every sector of the healthcare ecosystem, organized The 15th Annual Personalized Medicine Conference at Harvard Medical School on 13–14 November 2019, to consider the regulatory, reimbursement and clinical adoption challenges facing personalized medicine today.

Participants concluded that personalized medicine has begun to deliver improved care by linking more sophisticated diagnostics and more effective therapies. They also acknowledged that its continued advancement requires system-wide consideration, which is far from easy in the context of today’s silo-based healthcare systems. Participants maintained that by collaborating with one another in entirely new ways, disparate stakeholders can leverage the tools underpinning personalized medicine to improve patient care and make better use of healthcare resources.

Day 1: Diagnosing, different

The conference program demonstrated how cross-sector cooperation can address the challenges associated with diagnosing and preventing diseases through personalized medicine.

Participants noted the emergence of new tools that go beyond the use of genetic testing to uncover signature mutations associated with late-stage cancers, which has been a hallmark of personalized medicine for nearly a decade. The continued advancement of artificial intelligence, data analytics, genomic sequencing, liquid biopsies and proteomics, they suggested, may allow physicians to detect the onset of disease at its earliest stages, thereby mitigating the need for more expensive treatment of devastating late-stage diseases. In light of escalating healthcare costs around the world, panelists stressed the urgency of capitalizing on these opportunities to improve prevention strategies sooner rather than later.

“I actually think we get an A for technology,” said Michael J Pellini, Section 32 (CA, USA), during the conference’s first panel discussion. “If we can lower the rest of the barriers, how much shorter would the timeline be from discovery to patient impact? I think we can shrink that tremendously.”
In pursuit of this goal, representatives from multiple sectors of the healthcare ecosystem envisioned leaders from the diagnostics industry collaborating sooner with clinicians, IT industry representatives, payers and pharmaceutical researchers to ensure that final products and services meet the day-to-day needs of payers and healthcare providers. They also stressed the importance of protecting patients’ privacy as various types of health data are collected and integrated into healthcare work streams.

During a session on ‘Wellness in the Workplace’, moderator Jay G Wohlgemuth, Quest Diagnostics (NJ, USA), highlighted partnerships in pharmacogenomics and preventive medicine to demonstrate how employers and genetic testing companies may work together to deliver better patient care without sacrificing legal protections or patient privacy. As part of one such partnership, Jefferson Health worked with Color Genomics to sponsor third-party genetic testing of Jefferson’s employees. To address concerns over the potential for inappropriate inducement of genetic testing about disease risks by an employer that pays for insurance benefits on behalf of its employees, the institutions arranged for Color to independently manage the genetic data collected as part of the program, instead of sharing the data with Jefferson Health. Karen E Knudsen, Thomas Jefferson University (PA, USA), noted that the strategy was enough to prompt participation from a much larger percentage of Jefferson’s employees than the institution had anticipated.

“We decided that even in aggregate we will not learn the genetic information of (our) employee pool,” Knudsen said, during the ‘Wellness in the Workplace’ discussion. “The benefit is for the employees to learn about their risk in their own way.”

**Day 2: Targeting treatment**

The conference also featured several sessions examining how cooperative business models may advance curative personalized therapies with unprecedented value propositions. At present, these therapies are challenging health systems that were designed in the era of cheaper daily maintenance medications.

As researchers gain a better understanding of the various molecular factors that can contribute to the development of a single disease in different patients, biopharmaceutical companies are increasingly drawn to customized treatments, some of which are designed to treat only one patient at a time. Meanwhile, ‘immunotherapies’ that re-engineer a patient’s own cells to defeat cancer are transforming pharmaceutical pipelines [3]. Panelists agreed that the challenging scientific questions and systemic implications associated with these new types of therapies do not always fit neatly into existing regulatory, payment and care delivery frameworks, largely because they must recoup research and development costs from fewer treatments administered to smaller populations of patients.

During a keynote fireside chat titled, ‘The Era of the Living Drug’, Carl June, University of Pennsylvania (PA, USA), who pioneered the personalized chimeric antigen receptor T-cell therapies that are revolutionizing cancer care, explained that “we need adjustment on how to deliver care through pay-for-performance.”

During a keynote address titled, ‘Preparing Policies’, Scott Gottlieb, American Enterprise Institute (DC, USA), warned that emerging Congressional efforts to address this challenge by decreasing the prices for various therapies may eliminate investment incentives and thereby “foreclose therapeutic opportunities.” Participants considered whether innovative drug development models and improved value assessment frameworks may better balance larger societal goals with those of individual institutions. During an interactive case study discussion titled, “Balancing Business and Social Objectives to Advance Personalized Medicine,” led by Richard Hamermesh, Harvard Business School Kraft Precision Medicine Accelerator (MA, USA), conference participants explored how and why a group of government agencies, nonprofit organizations and pharmaceutical companies came together to support the Dementia Discovery Fund. The case study focused on whether this disease-specific venture, which seeks to create meaningful new medicines for patients with dementia in part by capitalizing on the evolving science underpinning personalized medicine, may offer a viable model for the future.

**Conclusion**

During the concluding session of the conference, titled, ‘Toward a Shared Value Proposition in HealthCare: Pursuing Value-Based Solutions in Research, Regulation, Reimbursement and Clinical Adoption’, a commercial payer, an industry representative, a patient and a value assessment framework developer convened to review research, regulatory, clinical adoption and especially reimbursement solutions raised during the conference. The panelists considered these solutions in the context of the concept of ‘shared value’, which was defined by Mark R Kramer and Marc W Pfitzer in the *Harvard Business Review* for October of 2016 as the economically and socially desirable
result of “policies and practices that contribute to competitive advantage while strengthening the communities in which a company operates” [4].

Envisioning an era in which institutions work together to aggregate, integrate and learn from data about each patient’s genome, physiology, metabolism and environment to support the efficient deployment and refinement of more sophisticated personalized medicine strategies, the panelists agreed that the concept of shared value should drive future progress in healthcare.

“There is a need for multiple partners to come together to create resources that will benefit all stakeholders,” said moderator William S Dalton, M2Gen (FL, USA). “This will require not only data-sharing, but also the ability to collaborate and use these data. No one stakeholder can do it by itself.”

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