PMC PERSONALIZED MEDICINE COALITION

PERSONALIZED MEDICINE IN BRIEF

VOL. 15, FALL 2020

Developments in Brief

2020

JUNE 4

A team led by Dr. Apostolia M. Tsimberidou of MD Anderson Cancer Center publishes a peer-reviewed article flagging the drop-off across multiple studies between the number of non-small cell lung cancer patients with detected actionable mutations and the number of patients receiving genetically targeted therapies. The article ignites interest in studying the factors underpinning this "practice gap."

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SEPTEMBER 2

Medicare officials boost payment rates for CAR T-cell therapies, a groundbreaking class of personalized treatments. By signaling the federal government's willingness to pay for personalized treatments, the decision may encourage additional investment in personalized medicine.

PAGE 4

SEPTEMBER 25

In an op-ed published in *STAT*, PMC President Edward Abrahams warns that two Trump administration proposals developed to curb drug costs and streamline the path to market for diagnostics may unintentionally undermine the advancement of personalized medicine.

PAGE 12

SEPTEMBER 29

PMC launches an educational infographic prompting patients to consider 22 questions about personalized medicine when they are conversing with health care professionals. The initiative promises to encourage more discussion about personalized medicine between patients and providers.

PAGE 10

OCTOBER 8

Rep. Ben McAdams (D-UT) becomes the 10th member of Congress to join the bicameral, bipartisan Personalized Medicine Caucus since its launch in February. The caucus' growing momentum across the political spectrum reflects the personalized medicine community's progress in addressing the lack of awareness about the field on Capitol Hill.

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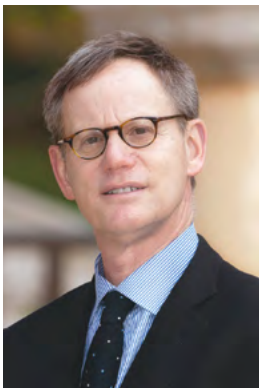
PRESIDENT'S BRIEF

Shifting Landscape Brings Opportunities, Challenges

by Edward Abrahams, PMC President



In the following essays, PMC staff members describe a shifting landscape for advancing personalized medicine that has given rise to both opportunities and challenges in the areas of public awareness, public policy and clinical affairs.

On the one hand, as PMC Vice President for Public Affairs Christopher J. Wells explains on pp. 8–9, an increasing appreciation for the importance of biomedical innovation and human heterogeneity has primed public opinion for policies that put patients in their rightful place at the center of health care decision-making. An improved understanding of the significance of diagnostic testing, the rise of telemedicine, and a welcome emphasis on engaging historically underrepresented patient populations in clinical trials, for example, all bode well for a future in which medicine is tailored to each patient's biological characteristics, circumstances and values.

In the midst of this evolving environment, the Coalition has also found lawmakers on Capitol Hill willing to join the Congressional Personalized Medicine Caucus once they are educated about personalized medicine's potential benefits for patients and health systems. On pp. 4–5, PMC Senior Vice President for Public Policy Cynthia A. Bens shares an update on the growth of the caucus. She also spotlights favorable coverage policies emerging from the Centers for Medicare and Medicaid Services that may enhance patients' access to personalized chimeric antigen receptor (CAR) T-cell therapies and the molecular diagnostics underpinning personalized medicine.

On pp. 6–7, PMC Senior Vice President for Science Policy Daryl Pritchard, Ph.D., notes the record pace at which personalized medicines are coming to market, which the Coalition recently documented in *The Personalized Medicine Report: Opportunity, Challenges, and the Future*.

Still, the challenges ahead are formidable.

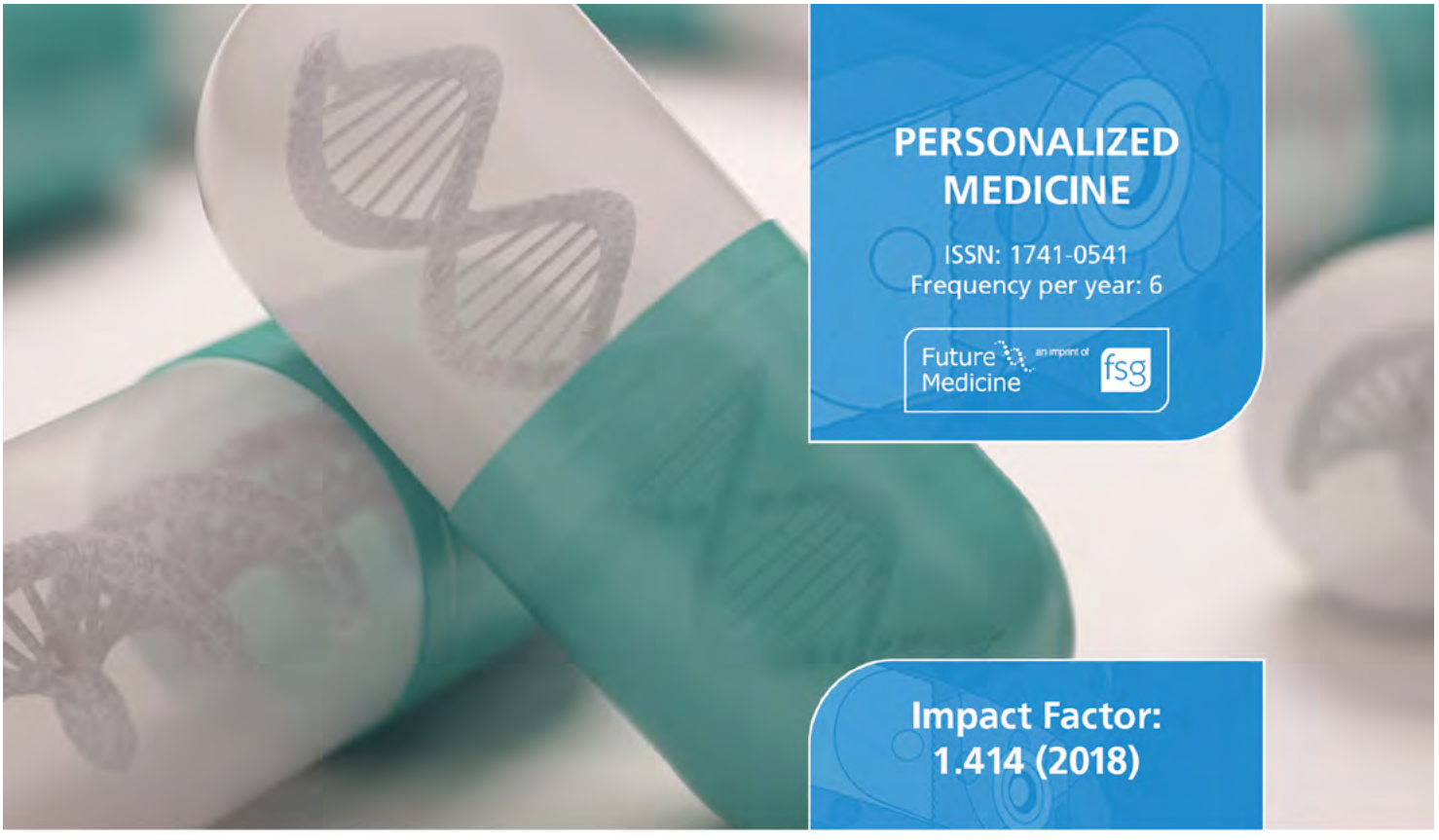
Pritchard outlines how an interrelated set of clinical adoption obstacles in personalized medicine have opened a "practice gap" in which patients who test positive for key biomarkers unfortunately never receive the corresponding treatments that would help them. In addition, as I explained in an op-ed for *STAT* in September, two Trump administration proposals, if they are implemented by the new administration, will "turn back the clock on biomedical progress" in personalized medicine by reducing the biopharmaceutical industry's incentives for investing in personalized treatments and disrupting bipartisan Congressional efforts to establish a clear path to market for laboratory-developed tests. And as PMC Vice President for Operations Faswilla Sampson and Director of Membership & Development Kayla Smith outline on pp. 10–11, patients are facing stiff headwinds related to education and access, making it difficult for them to advocate for more tailored health care.

In the months to come, PMC plans to tackle these challenges head on.

In addition to working with the Congressional Personalized Medicine Caucus to help educate a new Congress about the public policies that may advance the field, PMC will soon launch a new study titled "Addressing Practice Gaps in the Implementation of Personalized Medicine in Cancer Care." By uncovering the reasons some patients do not receive the right medicines, this research should help health care providers improve the quality of their care.

Also, to assist patients in becoming advocates for themselves, PMC has launched a new infographic encouraging them to consider 22 questions about personalized medicine when they are conversing with health care professionals. The infographic introduces the concept of personalized medicine and includes a list of questions for patients to ask during six key stages of their journey through the health care system.

Adding these initiatives to the Coalition's existing activities in education, advocacy and evidence development will, we hope, advance an era in which the right patient gets the right medicine at the right time.



PERSONALIZED MEDICINE

ISSN: 1741-0541
Frequency per year: 6

Future Medicine an imprint of fsg

Impact Factor: 1.414 (2018)

Personalized Medicine focuses on the path to the translation of 'omic advances into clinical practice, including areas such as:

- Implementation science & outcomes research
- Precision public health
- Participant engagement
- Educational strategies/workforce development
- Data science & analytics
- Ethical, legal, social & economic considerations

INDEXING

Chemical Abstracts I Current Contents®/ Clinical Medicine I EMBASE/Excerpta Medica I Essential Science Indicators I Journal Citation Reports/Science Edition I MEDLINE/Index Medicus I Research Alert I Science Citation Index Expanded (SciSearch®) I Scopus

"By covering the science, policy and business of this emerging paradigm, *Personalized Medicine* assists our understanding of where the field is heading, and should be essential reading for anyone with an interest in the subject."

Edward Abrahams, *Personalized Medicine Coalition, USA*

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PUBLIC POLICY BRIEF

Political, Policy Environment Evolves With Implications for Personalized Medicine

by Cynthia A. Bens, PMC Senior Vice President, Public Policy

As 2020 comes to a tumultuous end, a close look at political and policy developments related to health care in the United States reveals a landscape that has evolved considerably with implications for the future of personalized medicine. Policymakers' choices this year suggest the need to educate decision-makers about the importance of considering how their decisions impact the pace of progress in the field.

Still, many positive signs are coming from Congress and the Centers for Medicare and Medicaid Services that suggest a nascent understanding of the importance of personalized medicine to the American health care system.

Despite an exceptionally demanding political environment, 10 more members of Congress have joined the Congressional Personalized Medicine Caucus co-chaired by Sens. Tim Scott (R-SC) and Kyrsten Sinema (D-AZ) and Reps. Eric Swalwell (D-CA) and Tom Emmer (R-MN). This momentum suggests that ongoing advocacy efforts spearheaded by PMC and its allies continue to counteract a general lack of awareness about personalized medicine on Capitol Hill.

For its part, CMS has increased the amounts paid by the agency to reimburse hospitals for the costs of administering chimeric antigen receptor (CAR) T-cell therapies, an important class of personalized treatments. The new policy will expand patient access to these therapies by ensuring that hospitals can administer them to patients covered by Medicare without incurring unsustainable financial losses. It may also encourage investment in additional personalized therapies by signaling the federal government's willingness to adjust payment policies to ensure adequate reimbursement.

CMS followed its decision on CAR T-cell therapies with a proposal to simplify the reimbursement process for some laboratory testing services performed during the 14 days immediately following a patient's discharge from an outpatient hospital. By allowing laboratories to bill CMS directly for these services instead of securing reimbursement through interactions with hospital administrators, the streamlined policy will eliminate administrative burdens that may otherwise give hospitals an incentive to delay the diagnostic testing that makes personalized medicine possible. In its most recent letter to CMS Administrator Seema Verma, PMC notes that the revised date-of-service policy, like the changes to payment rates for CAR T-cell therapies, will help "support the appropriate deployment of personalized medicine in the U.S. health care system."

But policies that have emerged from the White House and the Department of Health and Human Services are less supportive of investment in personalized treatments.

For example, outgoing President Trump's "most favored nations" executive order on drug pricing, which proposes to tie the rates the federal government pays for various therapies to the lower prices established in more cost-conscious countries, would erode the biopharmaceutical industry's incentives for developing paradigm-changing treatments. Seeing that the vast majority of the largest markets in Europe and the United States are now almost universally unwilling to accept higher up-front spending on sophisticated personalized treatments even when they can eliminate downstream costs by permanently reversing the course of disease through just one or a few doses,

"A close look at political and policy developments related to health care in the United States reveals a landscape that has evolved considerably with implications for the future of personalized medicine."

the biopharmaceutical industry may pivot toward the development of cheaper one-size-fits-all maintenance medications in the coming years, unfortunately offering fewer benefits to patients and health systems.

As PMC President Edward Abrahams opined in an op-ed recently published in *STAT* titled "Personalized Medicine is the Future of Health Care. Two Trump Administration Proposals Could Stymie It:"

"At a moment when advanced data analytics, artificial intelligence, and real-world evidence are yielding unprecedented insights about which patients should receive which therapies, international reference pricing will rob the United States of an opportunity to stay ahead of its peers by establishing value-based payment rates for therapies that move us away from one-size-fits-all, trial-and-error medicine and toward personalized medicine."

THE CONGRESSIONAL PERSONALIZED MEDICINE CAUCUS

Despite a demanding political environment and the lack of awareness about personalized medicine on Capitol Hill, advocacy efforts spearheaded by PMC and its allies have helped prompt 10 members of Congress to join the Congressional Personalized Medicine Caucus since it was launched earlier this year by Sens. Tim Scott (R-SC) and Kyrsten Sinema (D-AZ) and Reps. Eric Swalwell (D-CA) and Tom Emmer (R-MN).

Co-Chairs

Sen. Tim Scott (R-SC)
Sen. Kyrsten Sinema (D-AZ)
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Rep. Tom Emmer (R-MN)

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Rep. Roger Marshall (R-KS-1)
Rep. Ben McAdams (D-UT-4)
Rep. Cathy McMorris Rodgers (R-WA-5)

SCIENCE POLICY BRIEF

Researchers Turn Attention to 'Practice Gap' as Studies Show Failure to Align Treatment With Genetic Testing Results

by Daryl Pritchard, PMC Senior Vice President, Science Policy

"A genetic test alone is not going to improve health outcomes; the potential of personalized medicine is that the insights from the test and the actions taken as a result will do so."

Former LabCorp Chairman and CEO David P. King's remarks during *The 14th Annual Personalized Medicine Conference at Harvard Medical School* summarize the insights emerging from recently published studies about the value of multi-gene panel testing in non-small cell lung cancer (NSCLC), a clinical area where personalized medicine has made one of its largest footprints.

As explained in a commentary article published in *Clinical Lung Cancer* this Summer by MD Anderson Cancer Center Professor Apostolia M. Tsimberidou, M.D., Ph.D., and a team of colleagues from Qiagen, Thermo Fisher Scientific and PMC, where Tsimberidou serves as a Board Member, two recent studies examining the clinical and economic value of next-generation sequencing (NGS)-based diagnostic testing compared with single-gene testing demonstrated statistically insignificant improvement in population-level overall survival for NSCLC patients with only a moderate incremental cost-effectiveness ratio. The data also demonstrated, however, more significantly for the future of personalized medicine, that many patients with actionable mutations did not receive the targeted therapies that would have helped them and that, moreover, would have increased the cost-effectiveness of the NGS-based tests.

This clinical practice gap — the failure to provide eligible patients with safer and more effective targeted therapies due to barriers in implementing personalized medicine — reminds us of the importance of understanding and addressing clinical adoption challenges to ensure that physician practices are keeping up with the rapid pace of scientific progress in personalized medicine. The latest edition of the Coalition's *Personalized Medicine Report* shows that the number of personalized medicines on the market in the United States has grown from 132 in 2016 to 286 in 2020, the largest four-year increase since the Coalition began tracking this figure in 2008. More than 90 of these medicines are cancer drugs, many of which are approved for lung cancer patients.

It is in this context that PMC has partnered with data analytics and consulting company Diaceutics and health policy communications firm Reservoir Communications Group to study the reasons why so many NSCLC patients with actionable mutations are not receiving targeted treatment regimens. Led by a project steering committee consisting of experts from leading health care delivery institutions, industry, and patient groups, the Coalition will utilize the Diaceutics genetic testing database to draw conclusions about specific clinical practice challenges contributing to this practice gap and estimate the impact that different factors have on the delivery of personalized cancer care.

Our hypotheses about the possible contributing factors are in part grounded in what we already know about evolving clinical perspectives on genomic testing.

As discussed during an expert roundtable forum titled *Defining the Clinical Utility of Genomic Profiling in Cancer Care*, hosted in Washington by PMC in October of 2019,

"A genetic test alone is not going to improve health outcomes; the potential of personalized medicine is that the insights from the test and the actions taken as a result will do so."

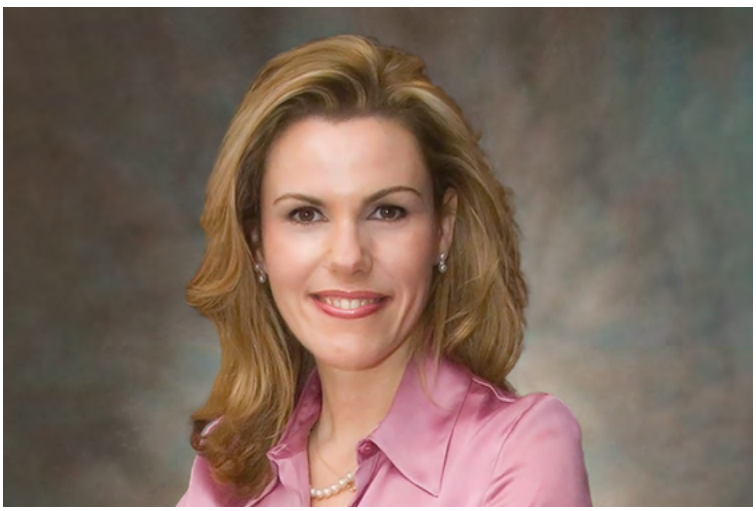
David P. King, former Chairman, CEO, LabCorp

if physicians are to be expected to order and interpret NGS-based tests appropriately and health care systems are going to invest in processes that ensure accuracy and efficiency in producing test results, they must have a complete appreciation of their clinical utility. PMC will soon publish a peer-reviewed report co-authored with the roundtable participants offering an updated definition of the clinical utility of NGS-based tests in cancer care. Applying this expanded definition may encourage the evidence-based use of genomic testing in clinical cancer care by helping physicians, payers and patients recognize the full range of benefits provided to patients and the health care system.

Even when genomic tests are ordered and targeted therapies are recommended, they may not be covered or adequately reimbursed by payers, which are under increasing pressure to control health care costs. And patients themselves may be reluctant to consider personalized treatment options based on real or perceived concerns about increased out-of-pocket expenses. According to a public opinion survey PMC conducted in 2018 to assess perceptions of personalized medicine, 59 percent of American patients worry that they "might not be able to afford a personalized approach to health care."

With these obstacles in mind, Tsimberidou and other proponents for personalized medicine are increasingly focused on reshaping health care systems in pursuit of personalized medicine's benefits for patients and health systems.

"If we focus our energy and efforts on the discovery of new and effective targeted agents, optimize the treatment selection process based on patients' characteristics, expedite the drug-approval process, and eliminate inefficient processes and unnecessary costs, we will accelerate the implementation of precision medicine," Tsimberidou explains.



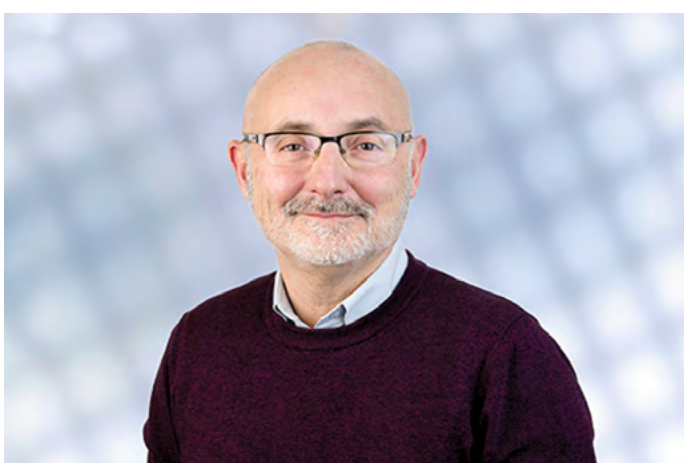
In a commentary article recently published in *Clinical Lung Cancer*, a team of authors led by MD Anderson Cancer Center Professor and PMC Board Member Apostolia M. Tsimberidou, M.D., Ph.D., notes that non-small cell lung cancer patients for whom next-generation sequencing (NGS)-based diagnostics revealed actionable mutations often do not receive the corresponding targeted therapies. PMC has begun to study the reasons for this "practice gap."

PUBLIC AFFAIRS BRIEF

Proponents for Personalized Medicine Note Increasing Appreciation for Field's Principles as 2020 Winds to Close

by Christopher J. Wells, PMC Vice President, Public Affairs

Even if most people have still never heard the words personalized medicine, an increasing appreciation for the importance of aligning health systems more closely with the needs of heterogenous patient populations stands to accelerate progress toward an era in which prevention and treatment plans are developed with more explicit consideration of each patient's biological characteristics, circumstances and values. Thus, health care leaders assessing the turbulence of the past nine months have begun, if slowly, to appreciate an evolving scientific, social and political landscape that begs for more tailored approaches to delivering medicine.



During a virtual seminar on September 3 titled *COVID-19 and Personalized Medicine: Current Status and Lessons Learned*, PMC Board Member Antonio L. Andreu, M.D., Ph.D., Scientific Director, European Infrastructure for Translational Medicine, explained how innovations emerging during a challenging year may nudge health care systems toward personalized medicine. "COVID-19 could be a very special moment for the development of personalized medicine [once the immediate challenges of the pandemic are overcome]," he said.

To be sure, the encouraging signs stem partly from the wildly varied ways that different patients have responded when they are infected with the SARS-CoV-2 virus. In an article, for example, that acknowledges the scientific principles underpinning personalized medicine, *The New York Times* on October 6 noted that then-President Trump's risk of developing serious symptoms during his battle with COVID-19 could not be appreciated without reference to his age, weight and the amount of the virus he may have been exposed to.

"Every patient is different, and doctors have learned that people can respond in different ways to the [same] disease," the *Times* explains.

But other key trends are woven more closely into the fabric of rapidly changing societies in the United States and around the world.

In the midst of ongoing discussions about the need for equity on multiple fronts as well as COVID-19's tragically outsized impact on racial and ethnic minorities, citizens are rightfully demanding that researchers do a better job of recruiting diverse groups of people for clinical trials. As National Alliance for Hispanic Health President and CEO Jane L. Delgado,

"Health care leaders assessing the turbulence of the past nine months have begun, if slowly, to appreciate an evolving scientific, social and political landscape that begs for more tailored approaches to delivering medicine."

Ph.D., and PMC President Edward Abrahams explained in *STAT* last year in an op-ed titled "Diversity in Clinical Trials Defines Good Science and Better Medicine," more diversity in clinical trials gives physicians the necessary data to understand how differences in race, ethnicity and gender may influence a patient's likelihood of responding to a particular treatment. Health care providers can then use this information to select the right treatment for each patient.

With a renewed emphasis on addressing the access challenges that have historically made it difficult for underserved populations to participate in clinical trials, patient advocates are encouraging federal officials in the United States to adopt public policies that would make it easier for patients to participate in trials occurring in other parts of the country by using digital health technologies to report medication usage and associated outcomes. This trend toward decentralized trials promises to help push us closer to an era of personalized medicine that is more responsive to the circumstances of individual patients.

"Decentralized trials provide more patients with access to investigational therapies, while also generating more data to inform scientific understanding," PMC Senior Vice President for Public Policy Cynthia A. Bens explained during a panel discussion the U.S. Food and Drug Administration hosted to consider updates for the next reauthorization of the *Prescription Drug User Fee Act (PDUFA)*. "Importantly, such an approach increases patient participation in research and can make it easier for diverse populations and patients in difficult geographic regions to access clinical trials."

In the wake of statewide stay-at-home orders designed to combat COVID-19, more patient-centered health care strategies are also making their way into — or rather out of — the clinic. According to survey results published in *Becker's Hospital Review* for October 6, the percentage of physicians using telemedicine to converse with patients while they remain in the comfort of their own homes has risen from 22 percent in 2019 to 80 percent this year. The increased use of telemedicine underscores the importance of delivering health care in ways that are most convenient and beneficial for patients. And payers' ongoing efforts to develop coverage policies that are responsive to this shifting landscape have underlined the importance of modernizing reimbursement policies as new opportunities in personalized medicine arise.

Reflecting on these developments during PMC's virtual seminar on September 3 titled *COVID-19 and Personalized Medicine: Current Status and Lessons Learned*, leaders from multiple sectors of the health care system considered how innovations emerging during a challenging year will reshape personalized medicine in 2021 and beyond. Their conversations anticipated an era in which new approaches designed to combat COVID-19 inexorably move health care systems toward personalized medicine.

"COVID-19 could be a very special moment for the development of personalized medicine [once the immediate challenges of the pandemic are overcome]," said PMC Board Member Antonio L. Andreu, M.D., Ph.D., Scientific Director, European Infrastructure for Translational Medicine.

PATIENTS' PATHS IN BRIEF

Educational, Clinical Integration Challenges Inhibiting Patients' Pursuit of Personalized Medicine

by Faswilla Sampson, PMC Vice President, Operations,
and Kayla Smith, PMC Director, Membership & Development

"You will have more control over your own destiny as well as the person who is choosing the medication for you."

This assumption about the future of medicine — which was expressed by a patient during focus groups that considered issues in personalized medicine organized by PMC in March 2013 — has been a point of emphasis in the past year as the Coalition has worked with patients and their caregivers to develop a series of initiatives designed to alleviate the day-to-day challenges faced by those who are enduring the cruel reality of ongoing disease symptoms or a diagnosis. These conversations have underlined the importance of attending to each patient's circumstances and values in order to advance a patient-centered personalized medicine paradigm.

The Coalition's discussions with patients have spotlighted several practical obstacles that they and their families encounter while engaging physicians and other medical professionals in pursuit of health care tailored to their needs and wishes.

The first is a lack of consumer-facing information about what personalized medicine is and why it matters. Although personalized medicines now account for one of every five drugs approved by the U.S. Food and Drug Administration, the Coalition's latest public awareness survey shows that only one-third of Americans have heard about the field. As a result of this educational disconnect and the busy schedules of overworked clinicians who are themselves hard-pressed to keep up with the rapid pace of progress in personalized medicine, many patients are learning about the availability of personalized prevention and treatment options only after one-size-fits-all approaches have failed them.

Second, for many patients, the complex world of health insurance remains a daunting obstacle, especially as it relates to the rapidly evolving reimbursement policies applicable to cutting-edge tests and treatments. Faced with stressful diagnoses, complex coverage policies and growing financial pressures, some patients may therefore forego personalized health care based on unwarranted concerns about reimbursement challenges.

To counteract these problems, PMC, with the support of Amgen, Foundation Medicine and Harvard Pilgrim Health Care, has published an infographic encouraging patients to consider 22 questions about personalized medicine when they converse with health care professionals. The new resource, titled *More Than a Number: Better Health Begins With You*, includes a description of the "Ins and Outs of Insurance Coverage" in the United States. PMC plans to expand on this work next year by creating a standalone website for the *More Than a Number* initiative. In addition to housing the Coalition's patient-facing educational resources, the site will include links to the online versions of articles PMC has published in the *USA Today* through its ongoing partnership with *Mediaplanet*.

But aligning health care with the biological characteristics and desires of every patient will require more than

> "The Coalition's discussions with patients have spotlighted several practical obstacles they and their families are encountering while engaging physicians and other medical professionals in pursuit of health care tailored to their needs and wishes."

consumer education. Continued engagement with health care professionals is also essential.

During PMC's roundtable discussions with the patients whose perspectives informed the development of *Moving Beyond Population Averages: A Patient-Centered Research Agenda Advancing Personalized Medicine*, participants stressed the importance of ensuring that health care professionals remain sensitive to all of the factors influencing patients' experiences during clinical interactions. The report encourages research that would help align the delivery of health care with patients' "diverse needs, diseases, backgrounds and experiences."

"This patient-centered research agenda should inform future studies that will provide patients, caregivers, and health care professionals with the information they need to make more informed health care decisions and, ultimately, improve the delivery of personalized medicine to patients in ways most meaningful to them," the report reads.

MEDIA BRIEF

From the PMC News Desk

Spotlighted in Qatari Daily, Remarks About Personalized Medicine From Congressional Personalized Medicine Caucus Co-Chair Raise Profile of Personalized Medicine on Global Stage, Highlighting Benefits Long Touted by Field's Proponents

An article published on October 14 in *The Peninsula*, a leading daily newspaper in Qatar, spotlights remarks about the significance of personalized medicine made by Congressional Personalized Medicine Caucus Co-Chair Rep. Eric Swalwell (D-CA) during his recent visit to the country, which has made major investments in a national precision medicine initiative. In highlighting benefits of personalized medicine long touted by its proponents, the article raises the profile of the field on the global stage.

"Personalized medicine can target treatments to only those patients who will benefit from them and eliminate the need for costly hospitalizations, making health systems more effective and efficient," Swalwell told the leaders of the Qatar Foundation, which co-leads the country's efforts in personalized medicine.

See *The Peninsula*: "US Congress Delegation Commends QF Efforts in Precision Medicine" (October 2020)

PMC Op-Ed Flags Trump Administration Policies That May Stymie Progress in Personalized Medicine

In an op-ed published on September 25 in *STAT*, PMC President Edward Abrahams explains how two Trump administration proposals developed to curb escalating drug costs and ensure that diagnostics for COVID-19 come to market as quickly as possible may unintentionally undermine the advancement of personalized medicine. The op-ed spotlights a drug pricing executive order that erodes the biopharmaceutical industry's incentives to invest in developing more sophisticated personalized treatments. It also addresses the Department of Health and Human Services' decision to weigh in on an ongoing debate about the Food and Drug Administration's authority to regulate laboratory-developed tests without input from stakeholders participating in Congressional discussions about the subject.

"The potential unintended consequences of [these policies] underline the importance of making careful decisions even during times of crisis," Abrahams writes.

See *STAT*: "Personalized Medicine is the Future of Health Care. Two Trump Administration Proposals Could Stymie It." (September 2020)

Bloomberg Analysis of COVID-19 Trials Shows Need for More Equitable Research to Inform Personalized Treatment Strategies for Patients With Underrepresented Racial, Ethnic Characteristics

In an examination of five COVID-19 trials published on July 30, *Bloomberg* shows that only one reported significant numbers of Black, Latino and Asian patients. In the absence of a more equitable biomedical research enterprise, PMC President Edward Abrahams warns in the article that it will be impossible to understand whether treatments for COVID-19 and other diseases work for patients with underrepresented racial and ethnic characteristics, thereby forcing physicians to rely on one-size-fits-all strategies that may fail to help certain patient populations.

"We have got to get a vaccine that works, and it's not necessarily going to unless we have diversity in trials," Abrahams said. "We know not all drugs work for all people."

See *Bloomberg*: "COVID-19 Clinical Trials Aren't Very Diverse and That's a Problem" (July 2020)

Positioning Personalized Medicine as Field Focused on 'Individually Tailored Drugs Costing Hundreds of Thousands,' *Kaiser Health News* Article Shows Need for Public Education About Cross-Sector Efforts to Advance Personalized Medicine

In a development demonstrating the need for additional public education about the scope and significance of progress in personalized medicine as well as the goals of its supporters from every sector of the health care ecosystem, an article published by *Kaiser Health News* on May 29 introduces personalized medicine as a field focused on "individually tailored drugs that can cost a patient hundreds of thousands of dollars." To advance a broader understanding of personalized medicine, PMC President Edward Abrahams wrote a letter to the editor of *Kaiser Health News* regarding the media outlet's characterization of the multi-stakeholder Coalition as a "pharma industry group."

"Pharmaceutical companies account for only 27 of PMC's more than 200 institutional members," Abrahams wrote. "The Coalition's collective membership, including patient organizations, health care providers and payers as well as industry groups, envisions a health care future that moves away from an inefficient one-size-fits-all, trial-and-error system to one in which each patient gets the right treatment at the right time based on his or her molecular profile, personal values and history."

See *Kaiser Health News*: "A Senator From Arizona Emerges As A Pharma Favorite" (May 2020)

See *Kaiser Health News*: "Letters to the Editor: June 23, 2020" (June 2020)

Exchanges in *Wall Street Journal* Consider Roles of Personalized Medicine, Public Health in Era of COVID-19, Underlining Value of Efforts to Foster Appreciation of Each

Following a "Saturday Essay" for May 9 titled "Has Personalized Medicine Been a Wrong Turn?," *The Wall Street Journal* published a series of responding letters to the editor a week later under the headline "Public, Personalized Medicine Each Have Their Place." The *Journal*'s exchange with its readers underlined the importance of fostering a continued appreciation for personalized medicine and public health as citizens and decision-makers grappling with COVID-19 embraced social distancing and other one-size-fits-all measures necessary to combat the pandemic.

In one of the three letters selected for publication, PMC President Edward Abrahams called attention to personalized medicine's successes, which had been downplayed in the original article. Referencing the experience of Stephanie Haney, a mother of two whose life has been extended for 13 years following a diagnosis of terminal lung cancer in 2007, Abrahams writes that we can discuss "until the cows come home" whether crizotinib, the targeted therapy used to treat Stephanie, "cost too much, too little, or just the right amount."

"What is not open to discussion," Abrahams contends, is whether personalized medicine has been a wrong turn.

See *The Wall Street Journal*: "Has Personalized Medicine Been a Wrong Turn?" (May 2020)

See *The Wall Street Journal*: "Public, Personalized Medicine Each Have Their Place" (May 2020)

CLINICAL LABORATORY TESTING SERVICES
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Invitae
Laboratory Corporation of America (LabCorp)
Quest Diagnostics

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Agendia NV
Agilent Technologies
Alacris Theranostics GmbH
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Caprion Proteomics
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Circulogene
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Diaceutics
Exact Sciences
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Helix
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Regeneron
Tango Therapeutics
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HEALTH INSURANCE COMPANIES
Harvard Pilgrim Health Care

INDUSTRY/TRADE ASSOCIATIONS
American Clinical Laboratory Association
BIO (Biotechnology Innovation Organization)
Biocom
PhRMA

IT/INFORMATICS COMPANIES
2bPrecise
Assurance Health Data
Change Healthcare
Concert Genetics
DNAnexus
Flatiron Health
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M2Gen
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P4-ML
PierianDx
Syapse
Translational Software
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Gilead
GlaxoSmithKline
Johnson & Johnson
Merck & Co.
Novartis
Pfizer, Inc.
Takeda Pharmaceuticals, Inc.

NUTRITION, HEALTH & WELLNESS COMPANIES
Preventive Partners

PATIENT ADVOCACY GROUPS
Accelerated Cure Project for Multiple Sclerosis
AiArthritis
Alliance for Aging Research
Alzheimer's Foundation of America
American Association of Kidney Patients (AAKP)
Bulgarian Association for Personalized Medicine
Canadian Organization for Rare Disorders
Cancer Commons
Clearity Foundation
Colorectal Cancer Alliance
CureDuchenne
Emily's Entourage
EveryLife Foundation for Rare Diseases
Fight Colorectal Cancer
Friends of Cancer Research
Global Liver Institute
GO_2 Foundation for Lung Cancer
HealthyWomen
International Cancer Advocacy Network ("ICAN")
LUNGevity Foundation
Multiple Myeloma Research Foundation
National Alliance Against Disparities in Patient Health
National Alliance for Hispanic Health
National Health Council
National Patient Advocate Foundation
SynGAP Research Fund
Team Trevor

PERSONALIZED MEDICINE SERVICE PROVIDERS
CareDx
Coriell Life Sciences
Genome Medical
Michael J. Bauer, M.D., & Associates, Inc.
Sema4
Sengenics
Tempus

RESEARCH, EDUCATION & CLINICAL CARE INSTITUTIONS
American Association for Cancer Research (AACR)
American Medical Association (AMA)
American Society of Health-System Pharmacists (ASHP)
Arizona State University
Association for Molecular Pathology (AMP)
Brown University
Business Finland
Cancer Treatment Centers of America
Cello Health BioConsulting
College of American Pathologists
Colorado Center for Personalized Medicine
CommonSpirit Health
Coriell Institute for Medical Research
Duke Center for Research on Personalized Health Care
Essentia Institute of Rural Health
European Infrastructure for Translational Medicine
Harvard Business School
Hospital Albert Einstein
HudsonAlpha Institute for Biotechnology
iCAN
Instituto de Salud Carlos III
Intermountain Healthcare
Johns Hopkins Individualized Health
King Faisal Specialist Hospital and Research Centre
MaineHealth Accountable Care Organization
Manchester University School of Pharmacy
Marshfield Clinic
Mayo Clinic
MD Anderson – Institute for Personalized Cancer Therapy
MITRE Corporation
Moffitt Cancer Center
Morehouse School of Medicine
National Pharmaceutical Council
Nicklaus Children's Hospital Research Institute
NorthShore University Health System
North Carolina Biotechnology Center
Precision Health Initiative at Cedars-Sinai
Qatar Biobank
Sanford Imagenetics, Sanford Health
Teachers' Retirement System of Kentucky
The Christ Hospital
The Jackson Laboratory
Thomas Jefferson University
Translational Genomics Research Institute (Tgen)
UC Davis Mouse Biology Program
University of Alabama, Birmingham
University of California, San Francisco (UCSF)
University of Pennsylvania Health System
University of Rochester
University of South Florida Morsani College of Medicine
Vanderbilt University Medical Center
West Cancer Center

RESEARCH TOOL COMPANIES
Illumina, Inc.
Thermo Fisher Scientific

STRATEGIC PARTNERS
Accenture
Arnold & Porter
Artisan Healthcare Consulting
Bioscience Valuation BSV GmbH
Blue Latitude Health
Boston Healthcare Associates
Bradford Power
Bruce Quinn Associates
Cambridge Cancer Genomics
Cambridge Healthtech Institute
ConText
ConvergeHEALTH by Deloitte
Defined Health
EdgeTech Law, LLP
Foley & Lardner, LLP
Foley Hoag, LLP
Goldbug Strategies, LLC
Health Advances, LLC
Hogan Lovells, LLP
Innovation Horizons
Innovation Policy Solutions
Jane Binger, Ed.D.
Jared Schwartz, M.D., Ph.D., LLC
KPMG
L.E.K. Consulting
McDermott Will & Emery
Michael Stocum
Neil A. Belson, LLC
Ogilvy
Priya Hays, M.D., Ph.D.
S D Averbuch Consulting, LLC
Slone Partners
The Journal of Precision Medicine
The Synergist
Truc Nguyen, M.D., Ph.D.
United States Pharmacopeial Convention (USP)
W2O
William P. Stanford, M.D., Ph.D.

VENTURE CAPITAL
GreyBird Ventures, LLC
Health Catalyst Capital Management, LLC
Kleiner Perkins Caufield & Byers
Section 32
Third Rock Ventures, LLC

PMC's Newest Members

Accenture
AiArthritis
American Association of Kidney Patients
American Society of Health-System Pharmacists
Assurance Health Data
Bluebird bio
Cancer Commons
Concert Genetics
Elevation Oncology, Inc.
Genomind
Gilead
HudsonAlpha Institute for Biotechnology
iCAN
IncellDx
KPMG
Michael Stocum
Morehouse School of Medicine
Priya Hays, M.D., Ph.D.
Oncocyte
Sema4
SynGAP Research Fund
The Synergist

MISSION: The Personalized Medicine Coalition (PMC), representing innovators, scientists, patients, providers and payers, promotes the understanding and adoption of personalized medicine concepts, services and products to benefit patients and the health system.

PMC
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