PRIORITIES ON THE HEALTH HORIZON

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"Knowing is not enough; we must apply. Willing is not enough; we must do." —GOETHE



for a healthier future



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PREFACE

Collaboration and partnership are key to the generation and application of new knowledge. This is particularly important for knowledge or evidence-based information that improves health and health care, given its dynamics and complexity. Many stakeholders—including patients, clinicians, researchers, and stakeholders from the broader health community—are intrinsically committed to collaborative partnerships to drive momentum and illuminate the path for progress. Engaging with stakeholders for guidance along the path in identifying priorities, generating evidence, and applying that knowledge toward improved health and health care delivery builds trust. Trust is both a foundational element and the *fuel* for such collaborative partnerships.

The National Academy of Medicine (NAM) and the Patient-Centered Outcomes Research Institute (PCORI) are aligned in their commitment to generating knowledge that improves health and health care, and in their commitment to leverage partnerships to support the shared goal of an equitable, stakeholder driven, evidence-guided, patient-centered system of care. The NAM's ability to marshal expertise by convening diverse and influential stakeholders spurs momentum and produces critical insights that drive action. PCORI's approach to patient-centered research centers on meaningful collaboration with stakeholders that values the unique contributions of all research partners-an important and vital paradigm for the field. As such, our two organizations worked together to facilitate an expansive dialogue with key stakeholders, to engender trust through a focus on shared commitments to progress on improving health for all Americans in the decade ahead. Through the discussions convened, these stakeholders provided generative and incisive perspectives that served as important reference points to PCORI's strategic planning process and development of its National Priorities for Health. This Special Publication, Priorities on the Health Horizon: Informing PCORI's Strategic Plan, is the product of these discussions and summarizes significant themes on the health horizon.

x | Preface

The partnership between our two organizations identified key issues and reinforced the need for engagement and collective learning—two bedrock aspects of PCORI's approach to its mission. Moreover, the meetings served to emphasize the facilitative role that both the NAM and PCORI play as trustworthy connectors across sectors, organizations, and stakeholders. Through engagement and collective learning, PCORI funds research on topics relevant to patients and stakeholders, thereby driving knowledge and catalyzing action. Given the myriad contributors to health and health care, strategic learning partnerships, purposeful collaboration, and cross-sector connection are instrumental to creating innovative approaches to transform health care to be more patient-centered, improving health outcomes for all, and building and sustaining trust with patients, their caregivers, and stakeholders across the health and research communities. We look forward to this progress.

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ACRONYMS AND ABBREVIATIONS

ACM	Association of Computing Machinery
AI	artificial intelligence
AMA	American Medical Association
ACO	accountable care organization
ACT	Adult Changes in Thought
AHRQ	Agency for Healthcare Research and Quality
API	application programming interface
CDC	Centers for Disease Control and Prevention
CER	Comparative Clinical Effectiveness Research
CLIIR	Center for Clinical Informatics and Improvement Research
CMS	Centers for Medicare & Medicaid Services
COVID-19	coronavirus disease 2019
ED	emergency department
EHR	electronic health record
FDA	Food and Drug Administration
GDP	gross domestic product
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
IU	Indiana University
JAMA	Journal of the American Medical Association

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LGBTQ+ LSU	lesbian, gay, bisexual, transgender, queer, and questioning Louisiana State University
MACRA MORhELab	Medicare Access and CHIP Reauthorization Act of 2015 Measuring & Operationalizing Racism to Achieve Health Equity
NAM	National Academy of Medicine
NASEM	National Academies of Sciences, Engineering, and Medicine
NIH	National Institutes of Health
NPAF	National Patient Advocacy Foundation
OCTO	Office of the Chief Technology Officer
ODPHP	Office of Disease Prevention and Health Promotion
OECD	Organisation for Economic Co-operation and Development
OMH	Office of Minority Health
ONC	Office of the National Coordinator for Health IT
OSU	The Ohio State University
РАНО	Pan American Health Organization
PCOR	patient-centered outcomes research
PCORI	Patient-Centered Outcomes Research Institute
PCORnet®	The National Patient-Centered Clinical Research Network
PFCC	patient and family-centered care
QUERI	Quality Enhancement Research Initiative
RWJF	Robert Wood Johnson Foundation
SARS-CoV-2	Severe Acute Respiratory Syndrome-Coronavirus-2
SIREN	Social Interventions Research and Evaluation Network
STEM	science, technology, engineering, and mathematics
UC	University of California
UCSF	University of California, San Francisco
VA	Department of Veterans Affairs
VUMC	Vanderbilt University Medical Center
WHO	World Health Organization
	PREPUBLICATION COPY—Uncorrected Proofs

EXECUTIVE SUMMARY

In response to a growing national awareness that the development and use of I new diagnostic, therapeutic, and preventive interventions had been occurring at a quickening pace—one far outstripping the evidence necessary to make informed decisions about their comparative advantage-the Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 as part of the Patient Protection and Affordable Care Act legislation. Geared to helping patients, families, clinicians, and other health care stakeholders make better informed health care decisions and improve care and outcomes, PCORI's initial mandate was to "identify national priorities for research, taking into account factors of disease..., gaps in evidence, practice variations and health disparities..., [and] the potential for new evidence" (PCORI, 2021). PCORI began funding comparative clinical effectiveness research (CER) in 2012 and, since then, has become a critical part of the U.S. research ecosystem, funding a substantial and growing portfolio of patient-centered outcomes research. With its portfolio, PCORI has crafted a new paradigm for engaging patients and stakeholders in the design, development, delivery, dissemination, and implementation of research findings on a wide array of topics. It has also focused on stimulating the development of new infrastructure imperative to facilitating the conduct of that research more quickly, in expanded settings and networks, and with a broader range of applicability.

In 2019, PCORI was reauthorized by Congress, adding two notable elements to the new statutory language. First, the 2019 amending legislation called for additional research priorities and prescribed that the research "reflect a balance between long-term priorities and short-term priorities, and [be] responsive to changes in medical evidence and in health care treatments." Second, PCORI received expanded authority to study "the full range of clinical and patient-centered outcomes [including] ... the potential burdens and economic impacts," which positions it to fund new research that can inform the value of health and

health care from the perspective of patients and families (U.S. Congress, 2019). The reauthorization provides a springboard for development of PCORI's next phase, currently being envisioned through a broad strategic planning initiative.

As part of this development process, and reflecting its deep commitment to broad stakeholder engagement, PCORI reached out to various stakeholder groups for input and enlisted the National Academy of Medicine (NAM) to organize and produce virtual meetings, which were titled Priorities on the Health Horizon. The overarching objective of the NAM meetings was to engage patients, clinicians, health system leaders, researchers, purchasers, and other stakeholders from the broader health community in identifying high-priority emerging issues on the health horizon. The key insights and themes from the meetings were summarized by the NAM organizers, with the guidance of a representative workgroup comprised of meeting participants.

Two particular recurring features of the conversations merit underscoring at the outset, one at the center of PCORI's mission and vision, and a second that will directly impact its prospects for success. As to the first, the discussions reflected the broad concurrence that health care has become increasingly complex given tremendous advances in medical science, and until patients and families are at the center of all aspects of the health care delivery system and related research, the system will fall far short of the moral imperative to improve health for all communities. Their perspectives and guidance are critical to inform the reorientation of the business of health care; deploy effective, affordable, and efficient practices; steward the collection and use of data to improve care; and ensure equity for all. The second was the related and recurrent observation that the nation's health system is built on a broken chassis of fee-for-service payment. As a result, progress in capturing the opportunities for research findings to catalyze improvements in the system's effectiveness, efficiency, and equity faces a daunting barrier at the outset. The sense of the discussions was that the public's interest will remain thwarted until a new chassis is built to replace what currently exists and that this is a potential area of opportunity for PCORI to consider research efforts focused on how emerging payment models may affect health care quality and health equity.

MEETING STRUCTURE

The first meeting of 40 invited participants on March 15–16, 2021, (https://nam.edu/event/priorities-on-the-health-horizon-informing-pcoris-strategic-plan-webinar), was designed to engage in "blue sky" thinking about emerging trends, priorities, and opportunities in health and health care. Day 1 was anchored by four macro topics: *emerging technologies; social and environmental factors; optimizing*

BOX 1

Macro-Level Topics and Included Concepts

Emerging Technologies: data use, interoperability, precision medicine, connectivity, engagement

Social and Environmental Factors: disparities, population health, social determinants of health, access

Optimizing Value: how "value" drives the health system and the health outcomes of people and populations

Infrastructure: systems, data, implementation, evidence mobilization, workforce

value; and infrastructure (see Box 1). These broad topics were purposely selected to stimulate a wide-ranging discussion and were then discussed in smaller breakout groups on Day 2. NAM staff prepared topic briefs to provide context for each topic and identify potential research questions (see Appendix A). The second meeting of 25 invited participants on April 27, 2021 (https://nam.edu/event/priorities-on-the-health-horizon-informing-pcoris-strategic-plan-meeting-two) was designed to consider two topics that were of particular priority for deeper discussion based on the initial meeting: (1) development of a patient-centered learning health system, and (2) how PCORI could use its unique mission, capabilities, and core activities to improve patient experience, outcomes, and value in health and health care. Both meetings were chaired by Neil R. Powe, M.D., M.P.H., M.B.A., from the University of California, San Francisco, and Zuckerberg San Francisco General Hospital, and were open to the public.

MEETING INSIGHTS

The critical discussion highlights from the two meetings identified **four cross-cutting themes** that are especially important to informing and shaping PCORI's opportunities and priorities over the next decade (see Box 2). Foremost is the imperative for strategies that will advance **health equity** and dismantle the structural racism that contributes so greatly to health inequities. Because of the magnitude of the related disparities, the structural factors that affect health status demand dedicated, well-designed research activities. Untangling how clinical factors and social determinants of health work alone or in combination to reduce or exacerbate inequities was viewed by meeting participants as an essential area

BOX 2

Cross-Cutting Themes

Health Equity: every person has an equivalent prospect to reach their full potential for health and well-being

Value Disconnect: discrepancy between prevailing health system incentives and forces, and the importance of the results to patients and society

Learning Health System: alignment of evidence, informatics, incentives, and culture for effectiveness, efficiency, equity, and continuous learning

Emerging Technologies: developing tools with varying individual and aggregate potential to affect human health and well-being

for PCORI to prioritize. An important consideration that resonated throughout the April meeting was the need to differentiate and examine both health equity and health *care* equity, given that they are multifaceted and intersecting but with distinct knowledge gaps and research questions.

A second theme was the apparent **value disconnect**—that is, the gap between perceptions of value in the economic sense and values in the moral, cultural, or personal sense. The disconnect between the current structure, financing, and organization of health care, and what patients, families, and communities need and value is increasingly acknowledged as a key driver to this disconnect. Timely access to responsive, affordable, high-quality, person-centered health care is essential, yet the experience for many is a health system that is fragmented, uncoordinated, expensive, inequitable, and of uneven quality. Meeting participants concurred with the fact that health care in the United States has been constructed on a "broken chassis" of fee-for-service payment, which is unable to deliver the results needed by the nation on most important performance dimensions. The fundamental need to build a new chassis is in the public's interest, rather than trying to fix what currently exists.

A third theme that cut across the discussions related to the need for an agile **learning health system**—one in which the alignment of evidence, informatics, incentives, and culture naturally improves and accelerates advances in health system effectiveness, efficiency, equity, and continuous learning. Given immense data capabilities, proliferation of potential sources of evidence, and rapid advances in technologies, there is a compelling need to be more nimble and coordinated in the ability to learn from every patient and family and embed evidence into health care at every

opportunity. Thus, an important element of the learning health system relevant to PCORI's core capabilities is the relationship between the data infrastructure supporting health and health care, and that supporting health research—inclusive of real-world data, common data models, and standards. The experience of National Patient-Centered Clinical Research Network (PCORnet[®]) with consolidating data models, ensuring data completeness, and applying insights from coronavirus disease 2019 (COVID-19) research can enable a more coherent, aligned approach to moving data from EHRs to research and then back into practice.

A final cross-cutting theme related to the need for a better understanding of the heterogeneous impacts of **emerging technologies** on patients, families, and communities. Technologies encompass cutting-edge medical and diagnostic therapies and digital innovations supporting health and care delivery, data use, and connectivity. Better understanding of their myriad effects and interplay will help create a more complete view of a person's entire experience and predispositions related to individual circumstances (from genetics to social needs). This could inform population health as well as reduce disparities. An observation that permeated both meetings was that the full potential of precision medicine, informed by predictive analytics, can only be realized if equity is its cornerstone.

Given the scope of the issues in the four domains considered during the Priorities on the Health Horizon meetings—emerging technologies, social and environmental factors, optimizing value, and infrastructure—a formidable set of pressing health and health care research needs were identified and discussed. In addition, certain fundamental strategic priorities emerged as basic and critical to progress in the field: (1) the need to reorient research perspectives and activities to patient and family priorities and values, and in particular those conditions that drive inequities; (2) the need to foster strategic learning partnerships across groups, organizations, communities, and sectors; and (3) the need to build the continuous learning infrastructure to produce new insights at the pace and scale necessary for health and health care improvement.

These three strategic priorities for the field align well with PCORI's adopted National Priorities for Health (see Box 3), which were released in June 2021 with an invitation for broad public comment. The adopted National Priorities orient PCORI's enhanced strategic emphasis on learning what works best for improving people's health and the health of the nation; stewarding the development of the infrastructure capacity to broaden and accelerate that learning process; quickening the pace at which lessons learned are disseminated and put into practice; reversing the persistent health inequities in the nation; and, through these efforts, accelerating health system transformation from one that is often too fragmented and inefficient to one that is integrated and continuously learning.

BOX 3

PCORI's Adopted National Priorities for Health

- 1. Increase evidence for existing interventions and emerging innovations in health
- 2. Enhance infrastructure to accelerate patient-centered outcomes research
- 3. Advance the science of dissemination, implementation, and health communication
- 4. Achieve health equity
- 5. Accelerate progress toward an integrated learning health system

In advancing these priorities, PCORI is signaling a bold commitment to deepening the systematic approach to ensuring that better, more reliable information is available to guide personal, community, clinical, organizational, and policy decisions to improve health and health care. PCORI further recognizes the importance of taking on a more facilitative role that draws broader public and private stakeholders to help mobilize synergy into building the aggregate strategy and infrastructure. Certainly, no single organization can meet the ever-increasing need to improve decisions central to health and health care delivery and outcomes. Given the size and complexity of these challenges, the imperative is for system participants to work together as seamlessly as possible to build the aggregate capacity to continuously improve learning and sharing throughout the system. PCORI's commitment to the themes of marshaling, connecting, integrating, and accelerating is a strong and promising step toward evidence-driven, equitable health in the decade ahead.

1

INTRODUCTION AND OVERVIEW

In response to a growing national awareness that the development and use of new diagnostic, therapeutic, and preventive interventions was occurring at a pace that both quickened and outstripped the evidence necessary to make informed decisions about the comparative advantages of different interventions, the Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 as part of the Patient Protection and Affordable Care Act legislation. Geared to helping patients, families, clinicians, and other health care stakeholders make better informed health care decisions and improve care and outcomes, PCORI's legislative mandate was to "identify national priorities for research, taking into account factors of disease..., gaps in evidence, practice variations and health disparities..., [and] the potential for new evidence."

PCORI began funding comparative clinical effectiveness research (CER) in 2012 and, since then, has become a critical part of the U.S. research ecosystem, funding a substantial and growing portfolio of patient-centered outcomes research. With its portfolio, PCORI has crafted a new paradigm for engaging patients and stakeholders in the design, development, delivery, dissemination, and implementation of research findings on a wide array of topics. Recognizing early on that suitable methods for patient-centered CER warranted a deeper evidence base, as well as standards that ensure methodological rigor, PCORI has also made commensurate investments in projects designed to improve the science and methods of patient-centered clinical research. Another element of PCORI's unique con-tribution to the research landscape since its inception was the development of PCORnet[®], the National Patient-Centered Clinical Research Network, in 2013. PCORnet[®] is designed as a collaborative resource to accelerate research by leveraging real-world clinical and administrative data from health systems and payers, along with patient-generated data.

Based on important contributions completed and in progress-including research findings, a new paradigm for patient-engaged research, and a national research infrastructure, PCORI was reauthorized by Congress in 2019, adding two notable elements in the new statute. First, the 2019 amending legislation called for additional research priorities and prescribed that, "Such priorities should reflect a balance between long-term priorities and short-term priorities and be responsive to changes in medical evidence and in health care treatments." In the process of engaging these additional responsibilities, PCORI's leadership and Board of Governors has undertaken a strategic evolution from national priorities for *research* to national priorities for *health* that will guide its funding of research and other activities, emphasizing the desired impact on health and health care.

Second, the legislation expanded PCORI's authority to study "the full range of clinical and patient-centered outcomes ... [including] ... the potential burdens and economic impacts." The ability to study this broader constellation of direct and indirect economic impacts, ranging from out-of-pocket costs to productivity to health care utilization, positions PCORI to fund new research that can inform the value of health and health care from the perspective of patients and families.

The reauthorization provides a springboard for development of PCORI's next phase, including development of its national priorities for health, its research agenda, and its strategic plan. As part of this development process and reflecting its deep commitment to broad stakeholder engagement, PCORI sought input via several forums, including its Advisory Committee meetings, internal discussions, and varied external stakeholder meetings. Insights from these forums have generated key considerations about how PCORI might maximize its impact and ability to address fundamental research topics in line with its mission and the most urgent questions in health and health care.

With this backdrop, PCORI enlisted the National Academy of Medicine (NAM) to organize and produce two virtual meetings, titled Priorities on the Health Horizon. The overarching objective of these meetings was to engage patients, clinicians, health system leaders, researchers, and other stakeholders from the broader health community to identify and discuss high-priority emerging issues in health, health care, and biomedical science and technology. This engagement leveraged the NAM's deep experience in convening experts on matters of significant national importance, including its longstanding thought leadership role in the realization of a learning health system, its recent work conducting assessments of the impact of COVID-19 on nine health-related sectors, and cross-cutting analyses of the most compelling system-wide priorities. With assistance from PCORI, the NAM identified participants for each meeting, including patients, researchers, clinicians, policymakers, and purchasers. A multistakeholder work group, comprising meeting participants, was established by NAM to co-develop this publication.

BOX 1

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Technologies: data use, interoperability, precision medicine, connectivity, engagement

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The first meeting of 40 invited participants on March 15-16, 2021 (https:// nam.edu/event/priorities-on-the-health-horizon-informing-pcoris-strategicplan-webinar), was designed to engage in "blue sky" thinking about emerging trends, priorities, and opportunities in health and health care. Day 1 was anchored by presentations on four broad topics: technologies, social and environmental factors, optimizing value, and infrastructure. Each topic was chosen intentionally for its ability to encompass several interrelated concepts (see Box 1). The same topics were then discussed in smaller breakout groups on Day 2. NAM staff prepared topic briefs to provide context for each topic and identify potential research questions (see Appendix A). The second meeting of 25 invited participants, on April 27, 2021 (https://nam.edu/event/priorities-on-the-health-horizon-informing-pcorisstrategic-plan-meeting-two), was designed to consider two topics of particular priority for deeper discussion based on the initial meeting: (1) development of a patient-centered learning health system, and (2) how PCORI could use its unique mission, capabilities, and core activities to improve patient experience, outcomes, and value in health and health care.

Both meetings were chaired by Neil R. Powe, M.D., M.P.H., M.B.A., from the University of California, San Francisco and Zuckerberg San Francisco General Hospital, and were open to the public. The NAM summarized highlights of both meetings for presentation to PCORI's Board of Governors and senior leader-ship, as background to their ongoing strategic planning discussions. Discussion highlights from each macro topic are synthesized below, including the broad stage-setting presentations that took place on March 15 and key points from the breakout group discussions on March 16, along with deeper topical examinations from the April 27 meeting.

At the March meeting, each breakout group used the following questions to guide the conversation:

- 1. What are the additional concepts or topics to consider as part of this topic?
- 2. What are the potential, disruptors, opportunities, and key trends on the horizon related to this topic?
- 3. What are the major obstacles or challenges to advancing progress related to this topic?
- 4. What else would it take for this topic to have a measurable and positive impact on health/health care in the next 5 years?

Similarly, at the April 27 meeting, the participants focused on two key questions that were designed to build on the discussions at the March meeting:

- 1. What will it take to create a patient-centered learning health system (with respect to infrastructure, technologies, incentives, and engagement)?
- 2. How can PCORI use its research strategies, unique role, and activities to improve patient experience, outcomes, and value in health and health care?

A synopsis of each broad topic is presented in the following chapters, followed by cross-cutting themes and insights for PCORI's national priorities and the field at large.

2

TECHNOLOGIES

CONTEXT

In this context, "technologies" encompasses myriad elements, including clinical and computational advances that have led to more precise, predictive, and personalized medicine, therapeutic and device innovations, and changes enabled by digital innovation (e.g., telehealth, virtual care, remote patient monitoring, and integration of devices/wearables to support prevention, diagnosis, treatment, and rehabilitation). The meetings described in this Special Publication focused on how to optimize the way that new technologies intersect with health and health care, including opportunities for emerging technologies to sharpen understanding of the comparative effectiveness of different treatments and ways technologies would promote health equity. Testament to the prospects for technologies to help accelerate patient and family engagement has been especially manifest in the rapid expansion and use of telehealth tools during the COVID-19 pandemic. Similarly, and at another site on the technology spectrum, is the possibility that applications of precision medicine, fueled by "omics" and clinical data and guided by artificial intelligence and machine-learning technologies, could eventually offer a more promising treatment journey for many patients if thoughtfully deployed. Technology also offers the ability to engage people and connect them based on affinities-including the shared illness experience. Given that health-related technologies are proliferating, PCORI has already begun to expand its research portfolio in this area, particularly with respect to its "Improving PCOR Methods" funding opportunities, which call out artificial intelligence and machine learning as priority topics.

COMPELLING RESEARCH QUESTIONS

Many technological innovations and ways of accelerating the use of data derived from health experiences are proliferating, particularly in the digital health space. Yet, the evidence base for many of these innovations has not fully kept pace. Hence, along with developing and leveraging new technologies, a corollary aspect is to examine intended and unintended consequences as these technologies diffuse at scale. To this end, future research could address topics such as:

- How might data use and data sharing be advanced in a way that takes advantage of progress made and lessons learned during a global health crisis?
- How can predictive and personalized interventions be deployed most effectively and with a clear focus on equity, given the current configuration of U.S. health care?
- In what ways could technology be leveraged to accelerate evidence generation and mobilization in practice?
- How can virtual care models be optimized and integrated with traditional care delivery and what are the ways in which virtual care can be tailored to patients' preferences and needs?
- What knowledge gaps must be addressed to better understand how patients/ caregivers might regard precision medicine, including behavioral, attitudinal, and other psychosocial aspects that affect uptake?

DISCUSSION HIGHLIGHTS

Joshua Denny, M.D., M.S., Chief Executive Officer of the National Institutes of Health's All of Us Research Program, gave a presentation at the initial meeting on the **role of technologies** in health and health care. Dr. Denny reflected on improving health via technology, large national cohorts, and precision medicine, using All of Us as the cornerstone example. The key objectives of All of Us are nurturing relationships over decades with 1 million diverse participant-partners, while developing a robust ecosystem of users and funders and a rich biomedical dataset that is freely accessible, easy to use, and highly secure. All of Us is geared toward the future of research and medicine, with the intention of creating a cohort of participants that reflects the United States with respect to demographic and geographic attributes. Participant partners help co-design research, can volunteer from anywhere, and can utilize their own devices to contribute data. Returning results to participants is a key aspect of delivering value to them and honors the time and effort of participating in research. Dr. Denny described complex

data aggregation and harmonization processes that he refracted through the lens of interoperability, noting that All of Us curates data from 16 electronic health record (EHR) vendors. To this end, thinking about the importance of investing in common data models as a research utility was noted. PCORI has already invested heavily in common data models via the PCORnet[®] initiative. An additional facet of All of Us with implications for the field is that it brings researchers to the data, rather than the data to researchers. Storing data in the cloud obviates the need to replicate infrastructure at every location and facilitates collaboration. Dr. Denny concluded by offering several examples of how medicine and technology could be transformed by 2030, including how research is conducted, greater diversity of both participants and researchers, EHRs as key research resources, and greater focus on privacy, trust, data security, transparency, and engagement (Denny and Collins, 2021).

The technologies breakout group noted many additional aspects for consideration in this space, including the creation of trustworthy technologies that are widely and equitably accessible and which enable people to be at the center of their own heath journey. Moreover, the use of data in practice needs to be fashioned in partnership with patients, helping them connect how evidence is related to their own health outcomes. At this point, the lack of an open and fully interoperable system prevents patients from being active participants at the research and care nexus. This is also hampered by the disconnect between health care research, public health, and quality improvement in addition to the lack of time for both clinicians and researchers to integrate innovations into the care delivery workflow.Yet, the same challenge could be reframed as an opportunity, in that aligned incentives, deliberate attention to centering technology on people/ patients, and concerted efforts to reduce the time demands of technologies could support better care and better outcomes. Considering the question, "what else would it take for technologies to have a measurable and positive impact in the next 5 years?" participants encouraged strengthening connections between academia and health systems, developing partnerships with technology platforms that exist at scale to advance health (including partners in nontraditional sectors), and taking stock of changes and accomplishments (e.g., telehealth) that have resulted from the COVID-19 pandemic to determine whether there are applications for the other identified obstacles to progress.

3

SOCIAL AND ENVIRONMENTAL FACTORS

CONTEXT

Health is influenced by numerous biological, behavioral, social, cultural, environmental, geographic, economic, health system, and public policy factors, most of which are interdependent at some level. Taken together (when adequately addressed and considered), these aspects can contribute to a more equitable experience of health for individuals and populations. The forces that influence health also contribute to the experience of health care, from prevention to late-life care experiences. Health equity focuses on removing unfair and unjust barriers to health, and health care equity concerns itself with efforts to remove barriers and ensure that all people have the resources and opportunities to access and achieve high-quality health care. By achieving health equity, societies have the opportunity to experience enhanced health and well-being for all, with better overall outcomes and long-term socioeconomic prosperity. The cumulative impacts of health inequities have translated into a decreasing life expectancy in the United States from 2016 to 2019, which was further exacerbated in 2020 by the severe impact of the COVID-19 pandemic, especially on populations with lower socioeconomic status, fewer resources, and disparate opportunities to access highquality health care (Adrasfay and Goldman, 2021).

COMPELLING RESEARCH QUESTIONS

Numerous knowledge gaps and unanswered questions related to social and environmental factors affecting health and health care were elucidated via the topic briefs and in the meeting discussions. These include:

• Where are the knowledge gaps with respect to interventions to tackle social determinants and environmental factors that influence health equity?

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- What does a vision of health equity look like across communities and care systems? What action is needed to realize this vision, and how can key national entities/agencies align their efforts and strategic priorities to reduce health inequities?
- What are the most promising trends, innovations, and movements that will promote and sustain health equity, and what investments are needed in order to cultivate research and action on emerging issues in health equity in the next decade?
- How can the research ecosystem, from the workforce to grants and funding, be optimized to promote comprehensive health equity research? Who are the critical partners from other sectors, including justice, education, and public policy, to engage in new research efforts?
- What actions are needed in order to *translate* evidence into actions, interventions, and policies that change systems and organizations to improve people's health and well-being?

DISCUSSION HIGHLIGHTS

To introduce the discussion of **social and environmental factors**, Rachel Hardeman, Ph.D., M.P.H., Associate Professor in the Division of Health Policy and Management and the Blue Cross Endowed Professor of Health Equity at the University of Minnesota School of Public Health, gave an opening presentation centered on three primary areas:

- 1. acute and longstanding health inequities that are caused or exacerbated by structural racism;
- 2. understanding of how the conditions of daily life (social determinants) experienced by historically oppressed groups have their roots in structural racism and impact health and well-being; and
- 3. insights into opportunities for improvement and transformation.

Dr. Hardeman offered a broad overview of how racism, operating as an underlying root cause, leads to structural policies, systems, and institutions—for example, in education, housing, employment, and financial access—that can add substantially and inequitably to health risks, health disparities, and poorer health outcomes. Dr. Hardeman also noted that inequities played out in real time as a consequence of the COVID-19 pandemic, with large disparities in cases, deaths, and access to testing and vaccinations in the Black populations of several states. She concluded by describing opportunities for individual and institutional

transformation, inclusive of research, policies, and personal inquiry. At the individual level, each person must think about their own role in dismantling structural racism and understand how racism has shaped discourse around disparities. For academic and research communities, she described opportunities to reframe research questions and methodology, noting that a more diverse set of questions, funded researchers, and research topics will move the entire field forward. Health system contributions to eliminating disparities will require dedicated and sustained attention, including desegregating the workforce and making training in structural racism a core competency in educating the clinical workforce. Finally, Dr. Hardeman offered several policy improvements at the state and national level that could produce meaningful changes, including a White House Office of Racial Equity, a comprehensive response to the COVID-19 pandemic, universal comprehensive single payer health care, and reparations.

Observing the interplay of these factors with patterns of justice, education, and social cohesion, the breakout group on social and environmental factors identified important related considerations. Person-centeredness is critical, noting that people do not experience social needs in one silo and health outcomes in another. Furthermore, the traditional culture of patient–clinician care organization interaction is contrary to the notion of the patient and family as "customer/ owner" of the processes involved. This compounds an already prevalent set of dynamics that can shape individual perceptions about their distance from the locus of control when it comes to their health. The ability to address the myriad factors affected by and adjacent to social and environmental factors is not solely the task of health care institutions—rather, there is a cross-sectoral need to look at all of these factors more holistically.

Noting a trend in cross-sectoral interest in equity arising from the twin forces of the pandemic and heightened awareness of racial injustice, this breakout group also underscored the centrality of sustaining the momentum, given the entrenched nature of the challenges. To that end, the group expressed the importance of bolstering the evidence base on effective interventions that can reduce the panoply of social and environmental factors that contribute to inequities, from implicit bias to food and housing insecurity, and examining both monetary and non-monetary costs of these inequities. Progress will depend on the committed engagement of all stakeholders, including patients, families, and other care partners who are personally affected by disparities, as well as policy makers and organizations that have been providing services to address social determinants of health. Broad collaboration is essential for attaining just health and systemic transformation.

4

OPTIMIZING VALUE

CONTEXT

Despite the fact that the United States spends twice as much per capita on medical services as any other developed nation—and 50% more than the second highest spending nation—its health performance ranks below the top 24 among the community of all nations. This is broadly attributed to financial incentives and system fragmentation that *promote volume over value*, resulting in unneeded services, inefficient care delivery, high prices, administrative waste, and missed prevention opportunities. In this context, addressing value entails transforming the relation-ship between health improvement, patient preferences, and economic investment. *Optimizing* value entails maximizing positive health outcomes while minimizing the costs associated with achieving those outcomes, notably through research and service provision. With PCORI's new authorizing legislation comes the opportunity to undertake research on different manifestations of value through the eyes of the patient, as measured via better outcomes, reduced burden, and other monetary and non-monetary costs of receiving care.

COMPELLING RESEARCH QUESTIONS

Value optimization holds potential for discovery, innovation, and research. In aligning incentives with optimal health outcomes, value-centric health system models are natural drivers of continuous learning. The ongoing pursuit of value— as a multidimensional, individually dependent concept—will necessitate constant innovation in health system infrastructure, delivery practices, patient engagement, and interventions with regard to individual and population health. To that end, several critical research questions emerge:

- In what ways does the current health and health care system create or impede value for different stakeholders across the care continuum?
- What would a "value optimized health and health care system" look like to patients and other stakeholders across the care continuum?
- In pursuing "value optimization," how would relevant initiatives balance costs of care with patient-centered outcomes, patient and family goals, societal values, and progress?
- What would it take to achieve patient-centered value optimization?

DISCUSSION HIGHLIGHTS

At the March meeting, David Muhlestein, Ph.D., J.D., Chief Strategy and Chief Research Officer for Leavitt Partners, provided an overview presentation on optimizing value. Dr. Muhlestein set the context by describing essential datapoints related to U.S. health care spending, as well as health care's dominant role in the economy, and the projected viability of the Medicare Trust Fund. Given this context, he then described the advent of value-based care as a chief mechanism for transforming the structure and financing of health care. It has been relatively successful as a lever to reconsider opportunities for coordinating care and building resiliency into the system through financial resiliency, although it has concentrated on payment reform, rather than complete delivery system reform. To this end, Dr. Muhlestein contrasted "Little v value," which focuses more incrementally on improving the clinical encounter, and "Big V value" which goes beyond improving the encounter with the patient to transforming the entirety of care delivery at a population level. He observed that the health care system will only attain Big V value by removing silos to look at the entire care delivery spectrum holistically and used the analogy of putting health care on a diet, stating that it is not enough to simply "change the items on the buffet," instead, there is a need to "change the restaurant." Dr. Muhlestein concluded with provocations related to system change and the need to rebuild health care on something other than a fee-for-service chassis. He encouraged a new worldview built around patients' needs and intrinsic capacity to achieve health and wellbeing. In contrast to the current capacity-focused business model (identify the best paid services, build capacity for those services, fill that capacity), the three components of patient-first business model would be to identify patients' needs, priorities, values and attributes, build low-priced services to fulfill needs, and prevent high-cost care. This, he acknowledged, is difficult work that will take a generation to bear fruit, but observable changes would take hold in 5 to 10 years if the work starts immediately.
In a generative breakout discussion, participants raised other concepts, including development of readily usable measures that define value and identification of best practices to optimize value for patients. PCORI's expanded remit to study economic impact along with other non-financial costs of care was viewed as a positive disrupter and key opportunity and could intersect with efforts to improve methodology and measurement related to social determinants of health (e.g., better understanding of financial toxicity and burdens of health care and the disproportionate impact on vulnerable/under-resourced populations). A number of obstacles were discussed, including incentive structures dominantly aimed at increasing service volume rather than patient outcomes, and a prevailing business model and governance structures oriented to profit margins. In addition, the pressure of increasing expenditures for health, in particular, from public revenue sources, diminishes funding for other critical investments in education, housing, and other health-related social needs. Participants offered that framing value in health care as a public health emergency, or framing health care transformation as a common social good, might help shift the prevailing narratives that more care equals better care, or that higher costs equal higher quality. The group agreed that PCORI could exploit the opportunity to develop a balanced portfolio of robust research that analyzes both value and burden at both the individual and community level.

The breakout group's insights sparked additional discussion at the March meeting that the concept of value through the eyes of the patient is not well understood. Hence, in the second meeting in April, special focus was given to this dimension. A panel discussion at the April meeting debated types of changes that might improve the value that patients derive from health care. A centerpiece of the discussion was the role of payment models and other influences on health improvement. The roles of primary care, transition to value-based care, and fragmentation across specialties were all discussed. A participant observed that fragmentation means that each specialty has a different business model, metrics, and incentives than does primary care. They observed that viewing this through the patient's eyes is pivotal, because many patients have long journeys, numerous providers, and the need for coordinated care. Developing a better understanding of this journey could yield shared knowledge about what works best for whom. Thus, participants urged consideration of ways to achieve widespread change outside of reforming payment models. Among the suggestions were to study the impact of accreditation, regulation, and education; rapid adoption of care models (e.g., telehealth); and effectiveness of newer care models in delivering value for different subgroups. Identifying ways to forge a complete shift from a transaction mindset in health care to one based on interaction and trust was seen as a research gap that PCORI could fill-providing evidence on the role of trusting relationships in support of better outcomes, experience, and value.

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5

INFRASTRUCTURE

CONTEXT

Infrastructure represents the foundational organizational and structural elements that enable a society to function. In the context of health and health care, the cornerstone elements of infrastructure include the diverse systems and settings in which care occurs; data generated by individuals and populations; policies that shape how health care is organized, financed, and delivered; the health care workforce; and the ability to utilize information to inform and improve outcomes. Infrastructure is also the backbone of connectivity, enabling individual patients, caregivers, and their communities, as well as other stakeholders, to engage with one another and to use information in their daily lives. Infrastructure as a whole is complex-including myriad elements ranging from the available diagnostic and therapeutic modalities available to the communication networks and systems, and on to the human capital involved-and these must work together seamlessly in pursuit of optimal health for all. The twin forces of the COVID-19 pandemic and rising awareness of ubiquitous, longstanding health disparities brought on by entrenched systemic racism have sharpened focus on the U.S. health care infrastructure as one that is brittle, fragmented, and unevenly distributed. Among other challenges, the pandemic illuminated key shortcomings in public health infrastructure, not only in the ability to exchange data and information rapidly to track cases and optimize care but also to quickly implement effective treatments and COVID-19 vaccines. Moreover, while the contributions of biomedical research grow exponentially, with thousands of rigorous peer-reviewed articles produced annually, leveraging the evidence at the point of care is an uneven proposition due to the heterogeneous nature and variable capacities of health care settings. The need to invest in health care infrastructure as a step toward realization of a patient-centered learning health system has only intensified in recent years.

COMPELLING RESEARCH QUESTIONS

Readying for another pandemic is widely viewed as an imperative in light of the impact of COVID-19 and includes attention and investments at the state and federal level focused on data, workforce, policies, and material. Concurrently, further research on how to actualize the learning health system will yield widespread benefits and ensure that biomedical research successes reap their full potential. This could have the corollary benefit of invigorating health care providers, in that clinicians (e.g., doctors, nurse, pharmacists, behavioral health practitioners) could see more immediate and tangible benefits of applying knowledge at the point of care. Finally, thoughtful attention to the emergent field of data justice (exploration of how the generation, collection, and use of data intersect with societal and structural inequalities), coupled with scrutiny of embedded biases in artificial intelligence, are two of many needed steps in effectively using data to mitigate health inequity. Compelling questions may include:

- What should a learning health care system look like to meet patients' needs in the next 5 years?
- What would be necessary to mount a coordinated and accelerated response to the next major public health challenge?
- What are the most effective approaches to dissemination and implementation of evidence, given the heterogeneity of U.S. health care?
- How can the wide range of data sources be leveraged most effectively to accelerate evidence generation and translation?

DISCUSSION HIGHLIGHTS

Rainu Kaushal, M.D., M.P.H., from Weill Cornell Medicine, provided the overview presentation on **infrastructure** at the March meeting, emphasizing five essential components of research infrastructure that have bearing on health and health care: *people*, *real-world data*, *systems*, *evidence generation*, and *evidence implementation*. Dr. Kaushal linked these infrastructure components to the learning health system, showing their relationships and interdependence. Dr. Kaushal observed that some elements of the U.S. infrastructure can be robust, but other parts need considerable attention, especially when the full continuum of prevention, screening, diagnosis and treatment, as well as health equity, is considered. The pandemic was particularly revealing in this regard. Development of COVID-19 diagnostic and treatment strategies worked comparatively well with the extant infrastructure; however, disparities were magnified. Dr. Kaushal described the INSIGHT

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Clinical Research Network (which she leads as part of PCORnet[®]) as an infrastructure exemplar. At the outset, she garnered cooperation from New York City health systems, which typically compete for market share, by establishing the value proposition that sharing clinical data via this network would improve patient care, population health, and research, thus bringing new ideas and expertise into New York's health care ecosystem. INSIGHT's infrastructure consists of a large research data mart and attendant logistical support; engagement of health system leaders, researchers, participants, and other stakeholders; and commitment to sharing expertise and supporting other people's research to further an active implementation and improvement capability.

Dr. Kaushal concluded by describing the *union* of precision medicine and precision prevention as the ultimate use case for infrastructure. By bringing realworld data to bear on diagnoses and treatments of diseases and applying those real-world data at scale for entire populations equitably, *precision health* becomes the blended product of informed and guided public health and health care delivery systems. Infrastructure for precision health spurs synergies and holistic thinking about how to make real-world data readily available for research; ensures that patients are engaged in evidence generation with an equity perspective; and then implements evidence at the point of need.

The infrastructure breakout group built on many themes from Dr. Kaushal's presentation, noting the importance of retaining and sustaining the research efficiencies spurred by the pandemic, including administrative, contractual, and oversight-related improvements, embrace of remote monitoring for clinical trials, and redoubled efforts to collaborate. The group noted that a key aspect of an effective infrastructure is diffusion of evidence to broader audiences in an understandable way, attentive to health literacy and data literacy. Reflecting on misinformation challenges of the pandemic, the group underscored the importance of communication and engagement as a part of an optimal infrastructure. The inherent complexity of the extant health care infrastructure creates challenges for patient engagement, such as fatigue from having to navigate the fragmented system. The group's concluding insight was that all stakeholders need a roadmap and clarity about the destination: what does a robust infrastructure for a patient-centered learning health system look like, how do we ensure that this infrastructure is further enhanced and sustained, and how can PCORI bring attention here and invest in weak spots?

Accordingly, development of a patient-centered learning health system was the second topical focus for the April meeting. Participants in that meeting used the frame "*what would it take*?" as they discussed the learning health system, its infrastructure, and PCORI's role. A notable theme was PCORI's ability to func-

tion as a *connector* that can drive research insights into practice, because this capability does not really exist anywhere in the health ecosystem. In this respect, both Sachin Jain, M.D., M.B.A., SCAN Group and Health Plan, and Atul Butte, M.D., Ph.D., University of California, San Francisco, noted the PCORI's potential role as an "effector arm" for the learning health system. PCORI's unique mission and attributes (e.g., PCORnet[®] data collaboration model, dissemination and implementation funding mechanism, engaged stakeholders) could combine to help it fulfill this function across the research enterprise and clarify the ideal infrastructure for learning what works best for whom.

6

CROSS-CUTTING THEMES

The critical discussion highlights from the two meetings identified four **L** cross-cutting themes, the dynamics of which are especially important to informing and shaping PCORI's opportunities and priorities over the next decade (see Box 2). Foremost is the imperative for strategies that will advance health equity and combat the structural racism that contributes so greatly to health inequities. Because of the magnitude of the resulting disparities, the structural factors that affect health status demand dedicated, well-designed research activities. Untangling how clinical and socioeconomic factors work alone, or in combination, to reduce or exacerbate inequities was viewed by meeting participants as a very important priority area for PCORI. As one participant noted, health is baked into everything people do-it is not separated but seamlessly integrated into daily activities—reiterating the importance of understanding how a person's experiences outside of a clinical setting can affect health. Furthermore, given that technologies and data facilitate the ability to gather information on an individual's health and can also provide them the tools to engage in and improve their health, it is crucial to examine health technologies and digitally driven advances through an equity lens. The concept of "health data poverty" was raised, referring to the fact that there are many people who will not benefit from advances because of systematic inequities in the quantity, quality, representativeness, and applicability of available health data (Ibrahim et al., 2021). An important consideration, raised by speaker Consuelo Wilkins, M.D., M.Sci, Vanderbilt University Medical Center, that resonated throughout the April meeting was the need to differentiate and examine both health equity and health care equity, given that they are multifaceted and intersecting, but with distinct knowledge gaps and research questions.

BOX 2

Cross-Cutting Themes

Health Equity: every person has an equivalent prospect to reach their full potential for health and well-being

Value Disconnect: discrepancy between prevailing health system incentives and forces and the importance of the results to patients, families, and society

Learning Health System: alignment of evidence, informatics, incentives and culture for effectiveness, efficiency, equity, and continuous learning

Emerging Technologies: developing tools with varying individual and aggregate potential to affect human health and well-being

A second dominant theme was the apparent value disconnect—that is, the gap between perceptions of value in the economic sense and values in the moral, cultural, or personal sense. The disconnect between the current structure, financing, and organization of health care and what patients, families, and communities need and value has become more and more apparent. Timely access to responsive, affordable, high-quality, person-centered health care is of the essence, yet the experience for many is a health system that is fragmented, uncoordinated, expensive, inequitable, and of uneven quality. These deficiencies have been further highlighted during the pandemic, with those from communities of color and low incomes being disproportionately affected not only by COVID-19 but also by mental health crises, isolation, and lack of access to care for other conditions. There are exemplars in the United States of groups that can help illuminate strategies to connect those value streams in redesigning a patient-centered system of care. Such exemplars, particularly the Accountable Communities of Health (https://innovation.cms.gov/innovation-models/ahcm) and Integrating Care for Kids (https://innovation.cms.gov/innovation-models/integrated-care-forkids-model) models, as well as federally qualified health centers (https://www. hrsa.gov/opa/eligibility-and-registration/health-centers/fqhc/index.html), offer natural learning laboratories and could be studied to assess the practical implications for large-scale health system transformation. Throughout the meetings, reference was made to the fact that health care in the United States has been constructed on the chassis of fee-for-service payment, which is now broken and unable to deliver the results needed by the nation on most important performance dimensions. Meeting participants resonated with the observation that the

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fundamental need to build a new chassis is in the public's interest, rather than trying to fix what currently exists.

A third theme that cut across the discussions related to the need for an agile learning health system—one in which the alignment of evidence, informatics, incentives, and culture naturally accelerates advances in health system effectiveness, efficiency, equity, and continuous learning. Given the already immense and ever increasing health and health care data bases and potential capabilities, with previously unimagined technologies and potential sources of evidence, there is a compelling need to be more nimble and coordinated in the ability to learn from every health-related patient and family experience, embedding evidence into health care at every opportunity. Because important policy issues are involved in the governance related to data quality, access, use, and sharing, PCORI is uniquely positioned to contribute to information development that may be useful to policymakers on approaches relevant to these and other issues important to learning health systems. This readily aligns with meeting participants' encouragement and support for PCORI's role as a connector across sectors, organizations, and stakeholders. Overall, attaining the learning health system capabilities at scale necessitates better alignment of incentives across stakeholders-health systems, academia, and patients and families-so that collective investments in improving the infrastructure provide tangible benefits to all.

An element of the learning health system that is especially linked to PCORI's core capabilities is the importance of stewardship of the relationship between the data infrastructure supporting health and health care and that supporting health research, inclusive of real-world data, common data models, and standards. Efforts to organize and harmonize health data entail considerable expenditures of time and resources across both academic and operational health care environments. For optimal functioning, these efforts require the availability of integrated, interdisciplinary teams of researchers, clinicians, and quality improvement experts to enable systematic, data-driven evidence generation from and application to practice, as well as engagement of patients and families to ensure that health data accurately represent their lived experience (Schleyer et al., 2021; Smoyer et al., 2016). The experience of PCORnet[®] with consolidating data models, ensuring data completeness, and applying insights from COVID-19 research can enable a more coherent and aligned approach to moving data from electronic health records to research and then back into practice. Furthermore, as several participants observed, the agility demonstrated by the health care and research communities during the COVID-19 pandemic offers insights into effective and synergistic collaboration strategies, ways to reduce administrative and data collection burdens, and novel approaches to conducting research. Such innovations and

alterations can foster lasting improvements to the overall research process, which then translates into the more robust, coordinated, patient-centered apparatus for learning, as urged during the discussions.

One other cross-cutting theme related to the need for a better understanding of the heterogeneity of the impacts of **emerging technologies** on patients, families, and communities. Some of this heterogeneity is a result of differences in environments, biology, structural factors, and related circumstances among different populations and subpopulations, and some of it is due to the impacts, directly or indirectly, on inequities related to the patterns of technologies' availability and use. Technologies encompass cutting-edge medical and diagnostic therapies and digital innovations supporting health and care delivery, data use, and connectivity, and better understanding of their myriad effects and interplay will help create a more complete view of a person's entire experience and predispositions related to individual circumstances (from genetics to social needs). This could inform population health as well as reduce disparities.

An observation that permeated both meetings was that the full potential of precision medicine, informed by predictive analytics, can only be realized if equity is its cornerstone. To this end, it is critical to understand who is represented in a given data set—as well as who is missing from it—and the assumptions that undergird the data. Upholding vigilance about the construction, validation, scaling, and ongoing monitoring of algorithms in health care is germane to PCORI's continued work on methodology standards and its portfolio of methods research. 7

PATIENTS SHAPING THE HEALTH HORIZON

In every discussion of the meeting series, anchoring focus and design on patients, families, and communities was emphasized as fundamental to reorienting the business of health care; deploying effective, affordable, and efficient practices; stewarding the collection and use of data to improve care; and ensuring equity for all. The predominant perspectives forging the design and implementation of systems of health and health care have heretofore been shaped by the vantage points of the knowledge, comfort levels, convenience, and reward systems of health care organizations and providers, but truly evolved and effective health systems will deploy success measures that start with the most fundamental needs and goals of those they serve.

Meeting participants were in agreement that bringing more attention to building trusting relationships and interactions, rather than just transactions in health care, is one way to drive and shape perspectives on value. Moreover, being more intentional about asking people what aspects of their health and health care matter most to them, and then incorporating these perspectives into broader assessments of performance and value, can help guide a research agenda for PCORI while raising awareness and building demand for care improvements. This broader imperative to understand "what matters" also entails bringing more voices to bear. PCORI engages with a sizable constituency of patients, families, and advocacy organizations. However, due to limited time, resources, capacity, or opportunity, many patients face barriers to participating in research, such as study inclusion criteria, cost or transportation constraints that preclude ability to complete research study visits, and fewer recruitment overtures extended to communities of color. Current systems are not structured to engage with the most vulnerable populations; thus, finding ways to raise the voices of the individuals facing the greatest challenges is essential for influencing policy, practice, and all phases of research—design, study implementation, analysis, and dissemination (Carter-Edwards et al., 2021). In discussions, there was broad concurrence that until patients and families are at the center of all aspects of the health care delivery system and related research, the system will fall short. The embedding of patient-centeredness as the starting point for PCORI's vision, mission, and program endows it with a leadership mantle of critical importance and advantage. 8

STRATEGIC PRIORITIES FOR THE FIELD

Given the scope of the issues in the domains considered in the Priorities Gon the Health Horizon meetings—emerging technologies, social and environmental factors, optimizing value, infrastructure, cross-cutting themes—a formidable set of pressing health and health care research needs was identified and discussed. In addition, certain fundamental strategic priorities emerged as basic and critical to progress in the field: (1) the need to reorient research perspectives and activities to patient and family priorities and values, in particular, those conditions that drive inequities; (2) the need to foster strategic learning partnerships across groups, organizations, and sectors; and (3) the need to build the continuous learning infrastructure to produce new insights at the pace and scale necessary for improving health and health care.

The first of these is directly linked to PCORI's origins: the search for better evidence on what works best, for whom, and under what unique circumstances for each individual. It has become clear that this means factoring in a much broader characterization of individual perspectives and conditions at work to determine individual receptivity, responses, and opportunities for interventions. In some respects, it means developing a strategy in which new technologies, new conceptualizations about health and health care, and new connections between health care needs and social factors are embraced, depending on individual circumstances. The recognition that this includes economic circumstances is now embedded in PCORI's expanded mandate to embrace financial realities as part of their remit. It also means using research strategies that accommodate and facilitate stronger relationships between the health care and social care systems that are beneficial to patients and families. From a research funder's perspective, it can mean attracting and funding applications from diverse organizations that, while close to daily lives of patients and families, may seem afield from more familiar research entities. Some studies mobilized during the COVID-19 pandemic used nontraditional lenses, which enhanced the understanding of problems and solutions for people, families, caregivers, and health workers on the front lines.

The importance of ensuring that research design accommodates an appropriate range of the factors shaping health prospects-and responses to interventionsrequires forging learning partnerships across groups, organizations, and sectors. At the most basic level, this means dedicated attention to ensure that there is strong strategic interplay and synergy among traditional funders of effectiveness research, like the National Institutes of Health, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Centers for Medicare & Medicaid Services, and the Food and Drug Administration, and certain voluntary organizations and philanthropies. But the importance of dedicated partnerships extends into other organizations, public and private, social and corporate, quantitative and qualitative, all of which are, at some level, important stakeholders in the applicability of research results. In principle, this can appear to add substantial complexity to an already complex challenge of reckoning with the multiple variables that influence health status and outcomes. But, in practice, enlisting and engaging these partnerships that add value to the generalizability and reach of discovery also builds stakeholders in the dissemination and use of results. A co-learning process, whether with patients and families or with multiple stakeholder organizations, adds and invests them naturally and additively in the process of dissemination and use. In addition, the forging of novel partnerships may help loosen the occasionally binding and self-perpetuating forces sometimes at play in more traditional academic research environments.

This raises the third strategic priority discussed: building a research infrastructure that is more seamlessly blended with routine care and even daily life. The aim of a continuously learning health system is to take better advantage of the digital environment now constantly generating structured and unstructured data from our experiences, introducing selective variability capture and analytic capacity, generating and testing insights, and accelerating the introduction of improved and tailored interventions accordingly. The infrastructure required has technical, economic, professional, cultural, and personal components, and its effectiveness depends upon multisystem interoperability, synergy, and incentives. Although still relatively early in its development, the PCOR net[®] infrastructure has helped to demonstrate the potential to use diverse real-world data in the conduct of pragmatic trials and observational research. That the build-out of the basic infrastructure components envisions operation across health care facilities of multiple sizes, interfaces with organizations in multiple sectors, while anchoring on the

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needs and preferences of individuals, underscores the need for stewardship of the connector and governance dimensions that represent common ground. Without a strongly committed steward, common ground can too easily become abandoned turf. The promise of the learning health system is profound in its technical achievability and, hence, its potential to accelerate progress toward a health system that is more effective, more efficient, more equitable, and more personal. Achieving that potential depends on careful attention to weaving together the multifaceted elements of the infrastructure.

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CONCLUDING INSIGHTS

Throughout the conduct of the Priorities on the Health Horizon meetings, PCORI was engaged in a strategic planning process for the decade ahead. Informed by the cooperative meeting series and extensive consultation with stakeholder communities, PCORI developed five proposed National Priorities for Health, released in June 2021 with an invitation for broad public comment. Presented below (see Box 3), the national priorities, adopted in October 2021, orient PCORI's enhanced strategic emphasis on learning what works best for improving people's health and the health of the nation; stewarding the development of the infrastructure capacity to broaden and accelerate that learning process; quickening the pace at which lessons learned are disseminated and put into practice; reversing the profile of persistent health inequities in the nation; and, through these efforts, accelerating health system transformation from one that is fragmented and inefficient to one that is integrated and continuously learning.

In advancing these priorities, PCORI is signaling a bold commitment: deepening the systematic approach to ensuring that better, more reliable information is available to guide personal, clinical, organizational, and policy decisions to improve health and health care but also to take on a more facilitative role that draws broader public and private stakeholders to help mobilize synergy into building the aggregate strategy and infrastructure committed. Certainly, no organization can meet the ever increasing need to improve decisions central to health and health care progress on its own. Given the size and complexity of the challenge, it is critical to meet the need for system participants to work together as seamlessly as possible to build the aggregate capacity to continuously improve learning and sharing throughout the system. PCORI's commitment to the themes of marshaling, connecting, integrating, and accelerating is a strong and promising signal for health progress in the decade ahead.

BOX 3

PCORI's Adopted National Priorities for Health

- 1. Increase evidence for existing interventions and emerging innovations in health
- 2. Enhance infrastructure to accelerate patient-centered outcomes research
- 3. Advance the science of dissemination, implementation, and health communication
- 4. Achieve health equity
- 5. Accelerate progress toward an integrated learning health system

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Appendix A

TOPIC BRIEFS FOR MARCH 15–16, 2021 MEETING

PCORI PRIORITIES ON THE HEALTH HORIZON MEETING— TECHNOLOGIES TOPIC BRIEF

Definition and Key Components

In this context, the term "technologies" encompasses myriad components, including clinical and computational advances that have led to more precise, predictive, and personalized medicine, therapeutic and device innovations, as well as changes enabled by digital technologies (e.g., virtual care, remote patient monitoring, and integration of devices/wearables to support prevention, diagnosis, treatment, and rehabilitation). The breadth and depth of this topic can include numerous offshoots given the many tools, instruments, and interventions available. Emphasis here is given to examples of how technologies intersect with health and health care and opportunities for emerging technologies to sharpen understanding of the comparative effectiveness of different treatments and illuminate opportunities to reduce health inequities.

Background and Current Profile

Health-related technologies are proliferating, which creates opportunities to optimize treatment at the point of care and to influence touchpoints with patients and consumers outside of clinical encounters. The FDA Center of Excellence in Digital Health observes that "digital tools are giving providers a more holistic view of patient health through access to data and giving patients more control over their health ... [offering] real opportunities to improve medical outcomes and enhance efficiency."That said, the broad implementation of electronic health records (EHRs)

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has yielded beneficial enhancements for care coordination and transparency, even as it has introduced new challenges for clinicians with respect to workflow, efficiency, and administrative burden. The ability to integrate data between EHRs and newer technologies (from smart watches to disease monitoring devices) is as overwhelming as it is exhilarating for those at the front lines of health care.

Potential applications of precision medicine, fueled by "omics" and clinical data and guided by artificial intelligence and machine learning technologies, could eventually offer more a promising treatment journey for patients with cancer, cardiovascular disease, and many other common and rare conditions. The promise of "P4" medicine that is "predictive, personalized, preventive, and participatory" has galvanized researchers, policymakers, patients, clinicians, and other stakeholders (Hood et al., 2012). Technology also offers the ability to engage people and connect them based on affinities-including the shared illness experience. This is evident in the rise of communities such as Patients Like Me, My Health Teams, and other digitally enabled patient groups hosted on social media platforms. Digital technologies support self-management, biohacking, adverse event reporting, and also research processes such as recruitment, symptom reporting, and adverse event monitoring. The rise of the COVID-19 pandemic has sparked new conversations about how digital technology could support not only tectonic shifts in health care toward virtual medicine but also decentralized clinical trials and more efficient research overall.

Illustrative Data Points

- From 2019 to 2020 (specifically, Surveillance Week 13), telehealth visits increased 154%, while ED visits underwent a marked decline over the same period (Koonin et al., 2020).
- More than 50% of individuals are able to access at least some of their own health information electronically (HealthIT.gov, 2018).
- Hospitals' engagement in interoperability improved by more than 50% in eight major U.S. cities since 2015 (Pylypchuk and Johnson, 2020).
- As of 2017, 94% of hospitals used their EHR data to perform hospital processes that inform clinical practice. EHR data is most commonly used by hospitals to support quality improvement (82%), monitor patient safety (81%), and measure organizational performance (77%) (Parasrampuria and Henry, 2019).
- The cost of sequencing the human genome decreased dramatically in less than 2 decades, from \$100 million in 2001 to \$1,000 in 2015.
- The National Institutes of Health (NIH) All of Us Research Program is a cornerstone of US precision medicine research, a \$1.5 billion initiative with more than 270,000 total participants enrolled as of December 2020 (NIH, 2020).

Emerging Trends and Dynamics That Shape Technologies in Health and Health Care

The COVID-19 pandemic obliged new thinking about health care delivery and unleashed creativity with respect to data-driven medicine. The motivation for rapid learning about the presentation and manifestations of the coronavirus led to rapid development and uptake of online symptom screeners and surveillance trackers and removed longstanding resistance to virtual medicine. Electronic health record data has also shown concerning trends related to the pandemic, namely the reduced use of preventive services, avoidance of needed chronic illness care, and reluctance to seek care for emergent symptoms. Another downside to this growing digital/social media ecosystem is proliferative misinformation about the virus itself and vaccines.

Technology tools also—ironically—illuminate the persisting digital divide. Broadband internet access is still unevenly distributed, as is health care itself. Although data are patchy, distressing trends in COVID-19 severity and vaccine distribution serve as a helpful use case for the varied applications of technology in health care and could help target care or resources where they are lacking. On the consumer level, "apps" and devices that support wellness, care delivery, and disease management are a growing category, underscored by investments in digital health, nearly doubling from \$7.4 billion in 2019, to \$14.1 billion in 2020 (DeSilva and Zweig, 2021).

Effects on Patients Along the Continuum of Their Health/Health Care Experience

Notwithstanding immense technologic advances, the health care system still maintains legacy modes for storing and transmitting health data, such as fax machines and CDs—modes that have been modernized in almost every other facet of contemporary society. Consequently, stakeholders are innovating around the edges, creating resources (data models, standards, and application program interfaces [APIs]) that enable interoperability and data liquidity. As health records are becoming increasingly digitized, tools that support digital exchange are paramount, especially for patients' experiences in screening, diagnosis, and treatment. Each of these elements of the care continuum can involve multiple clinicians or systems and demands seamless coordination, fueled by reliable data and connectivity. Technical challenges for clinicians and systems include managing the volume, quality, provenance, and availability of person-generated health data (Cortez et al., 2018). Empowered patient advocates, especially those contending

with complex chronic illnesses or rare conditions, are vocal about the need for technology-enabled care—often taking to social media to push for modernization, interoperability, and inclusivity.

With respect to prevention and health behavior, technology can serve as a potential adjunct. Wearable devices and mobile apps have been developed to support a range of fitness and wellness activities, including exercise, sleep, nutrition, medication tracking, mindfulness, and tobacco cessation, among others. Many of these embed accountability and motivation tools to encourage lasting behavior change. The COVID-19 pandemic led to an attendant surge of interest in fitness and exercise apps, with a 47% year-over-year increase in downloads globally from Q2 2019 to Q2 2020 (Chapple, 2020). Lower-tech interventions such as text-based behavioral supports (e.g., Text4Baby and SmokeFreeTXT) have shown promise, both with respect to engagement, reaching underserved populations, and rates of uptake. However, research on efficacy and effectiveness of technology to improve health and health care has not kept pace with the explosive growth of various digital and mobile health technologies, nor has the current evidence sufficiently explored differences by demographic subgroups.

The impact of technology on quality of life is decidedly mixed. Numerous reports cite deleterious effects of social media and gaming on adolescent mental health, including increased depression and anxiety and poorer sleep (Hoge et al., 2017; Riehm et al., 2019). Potential upsides for technology include decreased isolation and loneliness, particularly for older adults with limited in-person social support. Social media platforms are relatively recent, with Facebook and Twitter launching in 2004 and 2006, respectively. Hence, further examination of how personal characteristics intersect with use of digital technologies and social media tools, and the contribution of these technologies to health outcomes, quality of life, and general well-being warrants consideration.

Finally, the era of precision medicine has the potential to affect the entire care continuum. The opportunity to blend systems biology with machine learning offers tremendous promise for improving health and health care, while prompting complex questions about the "expected value of individualized care" (Basu et al., 2015). The heterogeneity of payment and delivery models in the United States suggests that applications of precision medicine discoveries may be equally heterogeneous. Significant research and investments in precision oncology, exemplified by targeted approaches to cancer prevention, diagnosis, and treatment, serve as a harbinger of opportunities in other clinical domains. Hence, understanding the value and equitable diffusion of precision medicine will only grow in importance as new discoveries are made.

Effects of Technologies on Discovery, Research, and Innovation

Emerging technologies—especially with regard to digital health infrastructure and data—are core utilities for transformative health, health care, and biomedical science and progress. If accessed consistently and used effectively, these technologies can help organizations engage in swift, available, and reliable health information sharing that delivers the right information to the right decision point, at the right time, for the best result according to patients' preferences. Tailoring and utilizing technology to apply this potential to the research industry layers a compounding effect of discovery atop the continuous learning promised. By leveraging electronic data sharing and a myriad of emerging digital tools, insights that have traditionally been out of reach for health care are possible, at a speed and quality that has yet to be experienced (OCTO, 2018). Determining best practices for using these tools, with a keen eye towards equity and health disparities, is expected to be a central priority on the horizon of American health and health care.

Related Initiatives

The potential of emerging technologies in advancing health and health care is evident—a fact that is both recognized and engaged by multiple stakeholders. Many of the efforts herein surround data governance and interoperability, with research networks such as PCORnet[®] as well as academic institutions, and individual state-level health information exchanges working to advance large-scale data collection, stewardship, and sharing. The federal government is also involved in this regard, with entities such as the Department of Health and Human Services (HHS), The Office of the National Coordinator for Health IT (ONC), and FDA working to advance the capabilities of digital health and data sharing to improve health system capacity and research functionality.

The private sector is also a key player in the technology sphere, with companies such as Microsoft, Google, Apple, and others building and improving tools that advance telehealth, remote patient monitoring, and artificial intelligence in health care. Partnerships between academic researchers, biotechnology/pharmaceutical and technology companies are accelerating the ability to analyze exabytes of structured and unstructured data, which can unlock the true promise of precision health. This work, and the related attention that is given to patient-facing interfaces, population health, and lifestyle management, is a hallmark of innovation to come. Health systems are also building collaborative approaches to using health data to study, predict, and improve health outcomes. Building on these effortsespecially with regard to equity—and collaborating with stakeholders to use this full spectrum of tools effectively will be critical to the next phase in the evolution of health and health care.

Compelling Questions: What Must We Address in the Years Ahead?

Given the enormity of the technologies space, engagement by all stakeholders is imperative for identifying and prioritizing questions that must be addressed in the years ahead. Along with developing and leveraging new technologies, a corollary aspect is to examine intended and unintended consequences as these technologies diffuse at scale. Some key questions include:

- How might we advance data sharing in a way that takes advantages of progress made during a global health crisis?
- How can predictive and personalized interventions be deployed most effectively and with a clear focus on equity, given the current configuration of U.S. health care?
- In what ways could technology be leveraged to accelerate evidence generation and mobilization in practice?
- How can virtual care models be optimized and integrated with traditional care delivery, and what are the ways in which virtual care can be tailored to patients' preferences and needs?
- What knowledge gaps must be addressed related to behavioral, attitudinal, and other psychosocial aspects that affect how patients/caregivers might regard precision medicine?

PCORI PRIORITIES ON THE HEALTH HORIZON MEETING— Social and Environmental factors topic brief

Definition and Key Components

Health is influenced by numerous biological, demographic, environmental, and socioeconomic aspects, many of which are interdependent. Taken together, these aspects can contribute to a more equitable experience of health-or health care-for individuals and populations. Health equity concerns itself with two steps: (1) reducing inequities between people with higher socioeconomic status and people with lower socioeconomic status and (2) meeting the absolute goal of health and well-being for all. By achieving health equity, societies have the opportunity to experience enhanced overall outcomes along with long-term socioeconomic prosperity. Achieving a more equitable society is also a noble goal in and of itself (Canning and Bowser, 2010). Today, the concepts, definitions, approaches, and frameworks underpinning social determinants and attaining health equity are passionately discussed and debated (Critical Public Health, 2008). Moreover, whether the extent to which resources or conditions that help a person meet daily needs is *deterministic* is also the subject of deliberation. Accounting for past, present, and emerging discussions on health, development, and equity, a report from the World Health Organization (WHO), Just Societies: Health Equity and Dignified Lives examines health equity through the lens of structural social, environmental, economic, and political issues and movements (see Figure 1).

Owing to their intersecting nature, components of social and environmental factors of health cannot be defined succinctly. Thus, the key components—a life-course approach to health, environmental factors, and social factors within the care continuum—will be defined and examined separately.

Background and Current Profile for Each Component

A Life Course Approach to Health

Inequities in health begin throughout someone's life course, starting from before birth and impacting an individual through older age. Disparities typically affect people across various identities such as race, geographic location, sexual orientation, gender identity, occupation, or disabilities. Knowledge gaps persist that relate to key points in the life course to use prevention or intervention efforts in settings such as schools, workplaces, or long-term care facilities.

The life course approach to social and environmental determinants also concerns itself with the impact of exposures to risk factors that worsen socio-

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Figure 1 | Framework from report of the Pan American Health Organization Commission on Equity and Health Inequalities in the Americas Indicating the Key Components of Social and Environmental Factors of Health.

SOURCE: Commission of the Pan American Health Organization on Equity and Health Inequalities in the Americas. 2019. Just societies: Health equity and dignified lives. Report of the Commission of the Pan American Health Organization on Equity and Health Inequalities in the Americas. Washington, DC: Pan American Health Organization.

economic and health outcomes throughout a person's life (Bezruchka, 2010). Exposures include various factors such as environment, education, housing and shelter, food, and access to public services and health care, all of which can impact health throughout the life course (see Figure 2). When accumulated throughout the life course, these exposures can accrete as biological stressors and manifest in older age as worse health outcomes: chronic disease, reduced functional ability, and intrinsic capacity. The disparity in the impact of exposures across the life course can lead to additional gaps between different demographic groups in the United States, with many examples pointed out in the form of life outcomes such as educational attainment, incarceration rates, housing policies, and income, and health outcomes such as developmental disorders, obesity, heart disease, and cancer (NASEM, 2017).



Figure 2 | Influences and actions along the life course. SOURCE: Davies, S. C. 2012. *Annual Report of the chief medical officer, volume one, 2011, on the state of the public's health.* London, UK: Department of Health.

The Environment and Human Health

WHO defines environmental health as all the "physical, chemical, and biological factors external to a person, and all the related behaviors." Environmental health consists of preventing and controlling morbidity and mortality resulting from interactions between people and their environment. Below are several key sources of negative environmental exposures.

- OUTDOOR AIR QUALITY: Poorer air quality is linked to higher morbidity and mortality from chronic diseases such as cancer and cardiopulmonary disease. High levels of unhealthy air emissions still exist for around 127 million Americans (ODPHP, 2020). Exposure to fine particulate matter, ozone, and nitrogen dioxide increases the incidence and burden of disease. In addition to these factors, inequities in location and place affect human health (Environmental Health Sciences Center, 2021).
- SURFACE AND GROUND WATER QUALITY: Contamination by infectious agents, chemicals, and heavy metals can result in highly detrimental health impacts, such as the 2014–2019 Flint Water crisis, which saw the drinking water for the city of Flint, Michigan contaminated with lead, Legionnaire's disease, coliform bacteria, and trihalomethanes (Ruckart et al., 2019).

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- TOXIC SUBSTANCES AND HAZARDOUS WASTES: Exposures to toxic substances such as pesticides and herbicides, paints, aerosols, cleaning products, fertilizers, and gasses are wide and mostly unknown.
- *HOMES AND COMMUNITIES:* A variety of indoor pollutants such as indoor air pollution; inadequate heating, cooling, and sanitation; structural safety; electrical and fire hazards; and lead-based paint hazards can impact health and safety.
- *PLACE AND GEOGRAPHIC LOCATION:* Geographic location in a marginalized or rural area can reduce physical access to health-promoting amenities such as health care facilities, parks, and supermarkets, and the means to access these facilities, such as public transport (Cushing et al., 2015; Hilmers et al., 2012).

Communities of color tend to live in environments with poorer air quality. High exposure to negative environmental exposures results in increased deaths from COVID-19, with case mortality rates and case fatality rates estimated between 11.3 percent and 16.2 percent. Cross-cutting disparities based on race and ethnicity have been observed with exposure to environmental hazards, poorer quality and unsafe infrastructure, and fewer health-promoting environmental amenities such as parks (Hilmers et al., 2012).

Social Factors Within the Care Continuum

The social determinants of health manifest throughout health care and population health systems, from prevention to late-life care experiences.

- ACCESS TO CARE: Marginalized populations experience decreased access to social protection, insurance, and health care due to disparities in economic opportunities and other factors such as structural racism and implicit bias. Several factors have been cited, but are not limited to, lower incomes, living in a U.S. state without the Medicaid expansion under the Patient Protection and Affordable Care Act, and living in a rural area. However, access to care does not always guarantee the quality of care. While disparities in long-term care facility access exist, research highlights that the wide gap in these facilities' quality is a larger issue (Smith et al., 2008).
- *INEQUITIES IN PATIENT EXPERIENCES:* Pervasive and troubling disparities in patient experiences and outcomes are also related to implicit racial bias from care providers and their impacts on patients. False beliefs about Black people's ability to bear pain have led to disparities in prescribing medications and even life-saving interventions to Black patients (Hoffman et al., 2016).

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• WORKFORCE DIVERSITY AND INCLUSION: Tied to implicit racial bias in the workforce are inequities in the demographics of the health care workforce. Nearly 62% of physicians and surgeons are male. White people constitute about 65% of the workforce, with Black people representing approximately only 5.6% of the workforce, far below the 11.6% share of the total U.S. population they constitute (DataUSA, 2021). Importantly, concordance of physicians and patients has been shown to affect utilization and costs, an area that warrants additional research (Jetty et al., 2021).

Emerging Trends and Dynamics

The Cumulative Social Impact of Exposures Across the Life-Course

The cumulative impacts of health inequities have translated into a decreasing life expectancy in the United States from 2016 to 2019. Life expectancy is expected to decrease in 2020 in light of the severe impact of the COVID-19 pandemic in the United States on Black and Latino populations, which recorded reductions in life expectancy at birth of 2.10 and 3.05 years (Andrasfay and Goldman, 2021). Key statistics across the life course include, but are not limited to, the following from each stage of life:

- *PRENATAL:* Before birth, Black and African American women are nearly three times as likely to die of complications related to pregnancy and childbirth than White women, a gap that has not narrowed (Lu, 2018). The same report attributes this phenomenon's causes to poorer health across the life course and disparities in access, safety, and maternal care quality.
- *INFANCY:* The infant mortality for Native Americans is 1.5 times the rate of White people. While White people experienced decreased infant mortality between 1990 and 2009, Native Americans did not (NASEM, 2017). A factor commonly cited for this occurrence is the historical forced displacement and mistreatment of Native American communities, people, and culture.
- *CHILDHOOD:* In 2017, 12.6% of Black and African American children had asthma compared with 7.7 percent of non-Hispanic White children (Carratala and Maxwell, 2020). The causes of this phenomenon are unclear, but children living below the poverty line or exposed to secondhand tobacco smoke exposure have higher rates of asthma (HHS OMH, 2021a).
- *ADOLESCENCE:* The number of suicide attempts by Hispanic females was 40% higher than that of adolescent non-Hispanic White females (Carratala and Maxwell, 2020). The poverty level has been attributed to causing reported psychological distress (HHS OMH, 2021b).

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- *ADULTHOOD:* Black and African Americans were 30% more likely than White people to die prematurely from heart disease in 2010 and twice as likely to die prematurely from a stroke (NASEM, 2017). This statistic demonstrates the compounding effect of severe impacts of exposure to negative social and environmental determinants.
- *OLDER AGE:* The odds of frailty among non-Hispanic Black and Hispanic older adults were approximately 1.5 times that of older White adults in 2020 (Bandeen-Roche et al., 2021). Here we observe the reinforced impact of cumulative exposures to negative social and environmental determinants.

Emerging research has also identified several factors causing decreases in life expectancy of White working-class populations without college degrees across their life course, as illustrated in the study by Deaton and Case in their seminal paper on "deaths of despair" (Case and Deaton, 2015). Collectively, these disparities can be attributed to several factors, including societal issues such as environmental pollution, unequal economic systems, and structural racism; to health systems and delivery issues such as the high access and cost barriers to primary and specialty care; and insufficient social protection and insurance coverage. However, more research is needed to assess the impact of factors on individuals, communities, and populations throughout the life course. Additionally, the research priorities could also describe the actions and efforts required to embed the connection between health and well-being at every life stage and the social, environmental, and health systems–related factors needed to enable this future (WHO, n.d.).

Impacts of Environmental Health

Environmental health is closely interrelated with the cumulative impacts of determinants across the life course. Despite this relationship, the compounding interaction between negative exposures can worsen without actions to address the environment.

Compelling Questions: What Must We Address in the Years Ahead?

The following list is intended to provoke contemplation of key knowledge gaps and unanswered questions related to social and environmental factors affecting health and health care:

Gaps in Research and Efforts

- Where are the knowledge gaps with interventions to tackle social and environmental factors that influence health equity? Can these gaps be tackled using a life course approach or at particular points in the care and public health system and continuum?
- While evaluating the multiple actions and efforts mobilized to improve health and well-being and reduce health equity, what populations, people, and communities have not been included or involved?
- How can the research ecosystem, from the workforce to grants and funding, be streamlined to promote comprehensive health equity research? Who are the critical partners from other sectors, including justice, education, and public policy, to engage in new research efforts?

Emerging Trends and Optimization

- How can learning health systems more quickly and effectively anticipate trends, guiding principles, and improvements and better focus interventions, prevention, and health promotion efforts?
- What are the most promising trends, innovations, and movements that will promote and maintain health equity?
- Where are investments needed to cultivate research and action on emerging issues in health equity in its next decade?

Toward the Future

- What actions are needed to *translate* evidence into actions, policies, and interventions that change systems and organizations to improve people's health and well-being?
- Looking toward the future and examining previous experiences in the field, what does a vision of health equity look like across societies and care systems? What action is needed to realize this vision?
- How can key national entities/agencies align their efforts and strategic priorities to reduce health inequities?

Related Initiatives

Numerous organizations have redoubled and redirected their attention toward racism, bias, injustice, and health equity. Increasingly, health equity is a crosscutting issue guiding the strategic priorities for many public and private entities. Addressing disparities can encompass data sharing, data justice, data ownership, pandemic preparedness and response, environmental and occupational health, and aging and longevity. Further research is needed to discern and target efforts to help historically unincluded communities and identities, including but not limited to racial and ethnic populations, people in rural locations, those with low incomes or low socioeconomic status, people with disabilities, people from the LGBTQ+ community, and those with limited English language proficiency. Meaningfully engaging and including these people and communities and advocating for their unique needs will assure concerted focus and maximize potential opportunities for improvement and transformation.

PCORI PRIORITIES ON THE HEALTH HORIZON MEETING— VALUE OPTIMIZATION TOPIC BRIEF

Definition and Key Components

Regarding health and health care, addressing value entails transforming the relationship between health improvement and economic investment. In this sense, *optimizing* value necessitates maximizing positive health outcomes while minimizing the costs associated with achieving those outcomes, notably via research and service provision. Because the concepts of "health" and "economic investment" can take on different meanings across the care continuum and between various stakeholder groups, "value" and the requisite actions needed to optimize it can vary across domains. Examining value within these contexts and determining its significance as a strategic issue are critical to improving and transforming health care.

Background and Current Profile

Even though the United States spends twice as much per capita on medical services as any other developed nation—and 50% more than the second-highest spending nation—its health performance ranks below the top two dozen among the community of all nations. This is broadly attributed to financial incentives and system fragmentation that promote volume over value, resulting in unneeded services, inefficient care delivery, high prices, excessive administrative costs, and missed prevention opportunities.

Public mistrust of the U.S. health care system—particularly surrounding profit motives—further challenges conversations about value. Inadequate transparency and low patient engagement create a dearth of public information on value, costs, and treatments, ultimately resulting in misunderstandings of value that further impede efforts to transform health and health care (Richmond et al., 2017). In 2020 and 2021, the dangers of this value gap have been illustrated starkly by the COVID-19 pandemic. The SARS-CoV-2 virus has wreaked havoc on individuals and families residing in the United States and the health system that serves them, and has exacerbated inequities. As compared with White, non-Hispanic persons, Black and African American individuals were 1.4 times as likely to contract SARS-CoV-2, 3.7 times as likely to be hospitalized by SARS-CoV-2, and 2.8 times as likely to die of SARS-CoV-2 (CDC, 2021a). This trend encompassed income disparities as well. As of February 2021, in terms of cumulative cases (per 100,000 individuals), U.S. counties with poverty rates higher than 17.3% expe-

rienced 22% more cases of SARS-CoV-2 than U.S. counties with poverty rates lower than 12.3%. In terms of cumulative deaths, this disparity is even starker; per 100,000 individuals, U.S. counties with poverty rates greater than 17.3% have experienced 50% more SARS-CoV-2 deaths than U.S. counties with poverty rates lower than 12.3% (CDC, 2021b) (see Figure 3).

The financial reckoning that accompanied these trends amplifies the need for change. Shutting down elective surgical procedures because of the pandemic dealt the health care system a deep financial blow, leading to a loss of 1.4 million health care jobs in the month of April 2020 and triggering calls for additional emergency funding for hospitals. The American Hospital Association estimated that U.S. hospitals and health systems experienced a \$200 billion shortfall over a 4-month period through June, with most of the lost revenue caused by canceled or postponed elective procedures. Owing to decreased patient volume, an additional \$120 billion in hospital financial losses were estimated from July to December 2020. Primary care practices have fared even worse, with 30% to 50% of practices either closing or being unsure of their continued operation. The fragility of our health care system has never been on such clear display, and the need for practice and payment reform has never been greater.



COVID-19 Cumulative Death Rate per 100,000 Population in United States, by Percentage of County Population in Poverty

Figure 3 | CDC COVID data tracker output for poverty classification. SOURCE: https://covid.cdc.gov/covid-data-tracker/?ACSTrackingID=USCDC_2067-DM45255&ACSTrackingLabel=Winter%20Holidays%20%7C%20COVID-19&deliveryName=USCDC_2067-DM45255#pop-factors_totaldeaths (accessed April 30, 2021).
Key Figures

IN TERMS OF THE NEED FOR A VALUE-ORIENTED SHIFT:

- As a proportion of gross domestic product (GDP), U.S. health care expenditures have consistently been greater than those of any other Organisation for Economic Co-operation and Development (OECD) country. In 2018, this accounted for 16.9% of the U.S. GDP (approximately \$3.5 trillion) (BEA, 2019). Despite this, the United States has experienced the lowest life expectancy of any OECD country since 1992 (Tikkanen and Abrams, 2020).
- In 2015, a bypass surgery procedure in the United States cost \$78,318. In the same year, Xarelto, a drug commonly used to prevent blood clots, cost \$292. In both cases, US pricing far exceeded that of its peers (FHCQ, 2020).
- Medical bankruptcy and financial toxicity have entered the lexicon in the last decade. As an example, research has found that people diagnosed with cancer are 2.5 times more likely to declare bankruptcy (Ramsey et al., 2013).

IN TERMS OF THE POTENTIAL THAT A SHIFT TO VALUE COULD ENTAIL:

- If properly applied, high-value services are projected to reduce negative health outcomes by 40% to 90%, and reduce spending by 20% to 50% (Health Rosetta, 2017).
- In addition to providing more than \$1 billion in net savings, Maryland's evolving approach to value-based care led to a 44% decline in potentially preventable complications between 2014 and 2016 (Maryland Department of Health, 2018; Smith, 2021).
- In 2019, accountable care organizations generated \$1.19 billion in total net savings to Medicare and achieved new program savings 3 years in a row (Verma, 2020).
- In terms of both patient care and financial resiliency, value-based models have proven to be exceptionally resilient to the effects of the COVID-19 pandemic (Feeley, 2021).

IN TERMS OF CURRENT TRENDS AND DRIVERS IN THE SPHERE OF VALUE:

• With a cumulative \$20 billion in funding, the Centers for Medicare & Medicaid Services (CMS) Innovation Center has launched 54 models aimed at moving the U.S. health care system toward value (OCTO, 2018).

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- Value-based services account for approximately 40% of Medicare fee-forservice payments, 30% of commercial payments, and 25% of Medicaid payments (OCTO, 2018).
- In the first year of the value-driven Quality Payment Program (initiated by the Medicare Access and CHIP Reauthorization Act [MACRA] in 2015), 95% of eligible clinicians participated in a Merit-Based Incentive Payment System (Health IT Playbook, n.d.)
- The CMS Primary Care Initiative is estimated to provide better alignment for more than 25% of Medicare fee-for-service beneficiaries (NASEM, 2017)

Emerging Trends and Dynamics That Shape Value in Health and Health Care

Intentional and informed patient-centered value optimization holds significant potential in incentivizing research and services that yield tremendous value for patients, families, and providers across the health and health care industry. Instead of simply encouraging service provision, a movement toward value should function to drive work that creates positive health outcomes, causing research and services that align with value to become common practice throughout the care continuum (Chernew et al., 2007).

Within this movement, a distinct focus on equity and engagement is both necessary and beneficial. By working with patients to build mutual understandings surrounding "value," the health system can catalyze both demand and momentum for services that are responsive to patient needs surrounding equity, efficiency, effectiveness, and continuous learning at every moment in care (Community Catalyst, 2021). Doing so with an especial focus toward equity will help advance a future in which, regardless of race or income, all individuals can fully realize their health-related goals.

Value optimization holds potential for discovery, innovation, and research. In aligning incentives with optimal health outcomes, value-centric health system models are natural drivers of continuous learning. The constant pursuit of value—as a multi-dimensional, individually dependent concept—will necessitate constant innovation in health system infrastructure, delivery practices, patient engagement, and interventions regarding population health. Likewise, in accruing both positive health outcomes and financial gains, success in a value-optimized system requires patient-centricity and constant improvement with regard to best practice (IOM, 2015).

PATIENTS	PROVIDERS	PAYERS	SUPPLIERS	SOCIETY
Lower Costs & better outcomes	Higher Patient Satisfaction Rates & Better Care Efficiencies	Stronger Cost Controls & Reduced Risks	Alignment of Prices with Patient Outcomes	Reduced Healthcare Spending & Better Overall Health

Value-Based Health Care Benefits

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

Figure 4 | Benefits of value-based health care.

SOURCE: NEJM Catalyst. 2017. What Is Value-Based Healthcare? https://catalyst.nejm.org/doi/full/10.1056/ CAT.17.0558 (accessed October 20, 2021).

Related/Supporting Initiatives

Multiple programs from states, providers, payers, and educational institutions are advancing a shift toward value. A selection of programs is listed in Box 4.

Compelling Questions: What Must We Address in the Years Ahead?

Optimizing value in health care has never been more timely or important, and identifying key questions to better understand the pathways to value optimization is a needed conversation across all stakeholders in health and health care. The COVID-19 pandemic further illuminated the necessity of optimizing value by revealing both flaws and opportunities in current care delivery models. In a value-centric conception of health and health care, the United States can also begin the long process of remediating health disparities—but refinement through patient-centered research will likely be essential to this process. Critical questions to address include:

- In what ways does the current health and health care system exemplify and defy value for different stakeholders across the care continuum?
- What would a "value-optimized health and health care system" look like to different stakeholders across the care continuum?
- In pursuing value optimization, how would relevant initiatives balance patient-centered outcomes and economic efficiency?
- What would it take to achieve patient-centered value optimization?

BOX 4

Value Movement Throughout the Health and Health Care System

Provider programs:

- Aledade
- Department of Veterans Affairs' Whole Health
- Geisinger Health System's "Proven Portfolio"
- Iora Health
- Nuka System of Care

State/local programs:

- Better Health Together
- Maryland Total Cost of Care Model
- Oregon's Coordinated Care Organizations
- Vermont All-Payer Accountable Care Organization Model

Payer programs:

• Blue Cross of North Carolina's "Blue Premier" Program

Multistakeholder programs:

- Network for Regional Health Improvement
- Innovation and Value Initiative

Educational programs:

- Dell Medical School Value Institute for Health and Health Care
- University of Michigan Center for Value-Based Insurance Design

PCORI PRIORITIES ON THE HEALTH HORIZON MEETING— INFRASTRUCTURE TOPIC BRIEF

Definition and Key Components

Infrastructure is defined as the foundational organizational and structural elements that enable society to function. In the context of health and health care, the cornerstone elements of infrastructure include the diverse **systems and settings** where care occurs, **data** generated by individuals and populations, the **health care workforce**, and the **ability to use information** to inform and improve outcomes. Infrastructure is also the backbone of **connectivity**, enabling individuals and communities to **engage** with one another and to use information in their daily lives. Infrastructure as a whole is complex—both composed of and influenced by myriad elements. And these elements must function seamlessly to yield better health for all. This topic brief explores the current state of health and health care infrastructure, including its role in engaging people in their health, the dynamics inherent in moving scientific evidence into practice, and the emergent trends and opportunities.

Background and Current Profile

The twin forces of the COVID-19 pandemic and rising awareness of ubiquitous, longstanding health disparities have sharpened focus on deficiencies of the U.S. health care infrastructure as one that is brittle, fragmented, and unevenly distributed. Among other challenges, the pandemic illuminated key shortcomings in the public health infrastructure, not only in the ability to rapidly exchange data and information to track cases and optimize care, but also the ability to efficiently implement effective treatments and COVID-19 vaccines. Early in the pandemic, numerous reports showed that COVID-19 disproportionately affected Black and Brown communities with respect to both incidence and severity (Abbasi, 2020; Azar et al., 2020). Conversations about these disparities have shown how structural racism permeates health care, including its delivery and the use of health data to guide person-centered decisions (Egede and Walker, 2020). An additional consequence of the pandemic is its toll on health care workers. Burnout and primary care shortages, already commonplace, have only accelerated in the last year (Bodenheimer and Sinsky, 2014; NASEM, 2019). A September 2020 survey showed that 64% were experiencing burnout, with the pandemic as a primary driver of increased stress (Frellick, 2020). Lastly, while biomedical research is robust and generative, with thousands of rigorous peer-reviewed articles produced annually, leveraging this evi-

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dence at the point of care is an uneven proposition, whether in academic medical systems, small primary care practices, or safety net care settings. Investments in our health care infrastructure have never been more urgent or necessary.

Illustrative Data Points

- As a proportion of the GDP, U.S. health care expenditures have consistently been above those of any other OECD country. In 2018, this accounted for 16.9% of U.S. GDP (~\$3.5 trillion), yet the United States has experienced the lowest life expectancy of any OECD country since 1992 (BEA, 2019; Tikkanen and Abrams, 2020).
- Clinician burnout increased by 9% in the period from 2011–2014 and has been exacerbated by the COVID-19 pandemic (NAM, 2021)
- Deaths attributed to COVID-19 are 1.1 to 2.8 times higher in people of color (CDC, 2021a)
- Generational shifts will affect site of care. Surveys show that 71% of millennials prefer to schedule appointments, access medical records, and receive appointment reminders via apps. A recent RAND study also showed that the 18 to 44 years age group also accounted for 43% of visits to retail clinics (RAND, 2016)
- Data from the 2003 National Assessment of Adult Literacy show that low health literacy affects approximately 36% of U.S. adults. Only 12% demonstrated proficient health literacy (Kutner et al., 2006)
- Implementation science, a burgeoning but new field, aims to close the gap between research and care by understanding tools, context, and other factors that promote uptake and integration of evidence-based practice. Since 2007, the annual Science of Dissemination and Implementation Conference has grown from a few hundred to 1,500 attendees (Glasgow et al., 2012).
- Local health departments have lost 21% of their operating capacity since 2008. Staffing shortages and uneven resources hindered the COVID-19 pandemic response, from data exchange to contact tracing (NACCHO, 2019)

Emerging Trends and Dynamics That Shape Health-Related Infrastructure

Multiple interdependent forces influence and shape the infrastructure for health and health care. Clinical encounters generate data points, and the aspiration of a learning health system is predicated on effective use of this clinical data for continuous improvement (IOM, 2010). However, the fragmented structure of U.S. health care means that data are collected, analyzed, and reapplied for improving

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care inconsistently—if at all. Since health is a continuous, longitudinal experience, unconfined to a brief clinical encounter, data generated outside the encounter—via social media, wearable devices, or geolocation information—are important potential complements to data contained in electronic medical records. Often, these sources of data are siloed and underutilized in clinician-patient interactions, hence this potential remains largely untapped. Data aggregation and governance are corollary issues that could revolutionize care, if remedied.

Many large technology companies are making inroads into health care, recognizing the size of this market and the valuable information it holds about individuals' behaviors, habits, and preferences. Digital health and "retail medicine" are fast-growing sectors of the health care ecosystem. From creating brick-andmortar primary care clinics to purchasing virtual care providers, the lines between nontraditional companies (i.e., large technology companies) and health care systems are blurring gradually.

Since people are increasingly responsible for more of their health care expenses, there is a slow but growing shift in perceptions about quality, cost, and experience. Today's consumers expect convenience, speed, personalization, and access for many facets of their day-to-day life, from buying groceries and airline tickets to entertainment and banking. This expectation has helped foster a drive for more convenient care. Yet, the data component of this infrastructure lags. A simple transaction at a retail pharmacy, such as a flu shot or blood pressure reading, or patient-generated health data from devices, wearables, and monitors, are unlikely to be seamlessly integrated into the medical record held by their clinician. The likely result may be duplicative or missing information about a person's complete health experience. A related facet of the health care consumerism movement is growth in direct-to-consumer advertising since FDA relaxed prescription drug advertising regulations in 1997, propagating a "quick fix" mindset and a medicalization of formerly ordinary symptoms. Clinicians may be ill-equipped to counsel their patients on underlying evidence about a given treatment owing to time and resource constraints.

Hence, despite substantial accumulations to the evidence base for many acute and chronic conditions, implementation of best-available evidence at the point of care varies widely based on factors such as the clinical topic, provider characteristics, and adaptability of the care delivery setting (Tricoci et al., 2009). Change management in health care is a cottage industry in itself, offering frameworks and models to support change and explain variation (Damschroder et al., 2009; Wagner et al., 1996). But the vast complexity of care delivery and range of permutations of contemporary medicine challenge the agility of even the highest performing systems. The COVID-19 pandemic illustrated the essential need for real-time data to drive understanding of care, with many clinicians turning to social media to share insights and inquiries, lacking a more robust information exchange capability. Importantly, the issues of data access for improving care are equally essential in the research context.

Infrastructure, refracted through the prism of data, access to high-performing health systems, and application of evidence could reduce *or* exacerbate health disparities depending on how society responds. Moral and ethical ramifications of this uneven infrastructure, and the imperative to create an equitable infrastructure, are further magnified when looking at effects on health care workers. A shortage of trained personnel hinders the ability to address patients' social needs (housing, food, and safety), which are inextricably linked to quality of life. Increased attention to and investment in community supports as a complement to clinical care could alleviate some of the pressure on the health care workforce and attenuate the deleterious effects of unmet social needs.

Effect of Infrastructure on Health and Health Care Experience

Research literature and patients' own accounts paint a picture of how many health care systems fall short of optimum with respect to preventive care, screening and diagnosis, treatment, and overall quality of life. How do the previously mentioned infrastructure elements contribute to variable health and health care? The following examples show how differences and deficits in U.S. health care infrastructure contribute to suboptimal outcomes and, in many cases, worsen health disparities:

- *PREVENTION:* based on the beneficial impact of the National Diabetes Prevention Program in clinical trials, CDC provided funding to widely disseminate it through community partnerships. However, a recent study of the implementation of the program found uneven access to it in urban versus rural counties (Ariel-Donges et al., 2020). Rural health disparities persist for other preventable conditions. In some cases, these could be mitigated by webor video-based approaches to care and health education. Yet, reliable broadband access is another infrastructure issue that is a prerequisite to delivering virtual preventive services.
- SCREENING AND DIAGNOSIS: The COVID-19 pandemic magnified deficiencies of the public health and health care infrastructure. Backbone capabilities such as delivery of reliable communication, venues for rapid screening, availability of testing materials, variable laboratory capacity, and demands on the work force combined to exacerbate surges in COVID-19

diagnoses in the United States relative to other countries. Factors, including occupation, living arrangements, and transportation access, have contributed to the disproportionate impact of COVID-19 on communities of color.

- *TREATMENT*: Given the complexity of cancer treatment, it is imperative to have reliable evidence at the point of care and access to the treatment itself. Research on new treatments is proliferating, including gene sequencing, immunologic therapies, and biomarker-driven treatment decisions. However, the cancer clinical trial infrastructure has long been a topic of concern, given its low accrual (especially of representative populations) and participant burden. Additional structural challenges include availability of skilled surgeons and oncologists and marshaling the unstructured real-world clinical data from disconnected care systems.
- *QUALITY OF LIFE:* Infrastructure has a compelling impact on quality of life, influencing conditions in which people live, work, learn, and engage with their communities. Access to clean water, transportation, stable housing, public safety, and healthful food are well-studied drivers of health outcomes at the individual and population level. Recent examples include the Flint water crisis, collapse of major interstates and bridges, and illustrations of "food deserts" that are associated with adverse outcomes.

Effect of Infrastructure on Discovery, Research, and Innovation

Given the heterogeneity of U.S. health care, opportunities for experimentation and innovation abound, as exemplified by new primary and virtual care models, and new data aggregation and sharing ventures by health systems and payers. Approaches to operationalizing the learning health system are accelerating in health systems and academic medical centers (Allen et al., 2021). In the patient/consumer space, recognition of the importance of community as an adjunct to clinical care has sparked new programs to connect individuals to resources that address basic social needs (food, shelter, safety, and transportation). However, despite exhortations to address critical workforce shortages, proposed solutions have had less traction. Rethinking scope of practice, licensure, and interstate regulations and further invigorating science, technology, engineering, and mathematics (STEM) programs in schools are opportunities in medical education that have not yet been fully exploited.

Related Initiatives and Connections

U.S. health care is a work in progress. Many groups are addressing current infrastructure challenges, and many have an explicit focus on reducing disparities in access and quality of care. Newer collaborative ventures, such as Truveta, that seek to leverage health data can be part of synergistic efforts to improve the health care infrastructure. The Healthcare Anchor Network is taking direct aim at the connection between the community conditions that create poor health and the hiring, purchasing, and investment decisions made by health systems. Connecting with these groups, among many other stakeholders, could have a lasting impact in the next decade. While not exhaustive, the following lists offer potential connection points.

Groups Centered on the Application of Evidence in Practice

- The Learning Health Community (grassroots endeavor to manifest a national learning health system)
- Department of Veterans Affairs' Health System's Quality Enhancement Research Initiative (QUERI) Programs
- AcademyHealth's Paradigm Project
- Institute for Health Improvement's Practical Playbook

Groups Centered on Connecting Stakeholders as a Lever for Health Care Innovation and Improvement

- Community Catalyst
- Families USA
- Network for Regional Health Improvement

Groups Promulgating and Applying Common Data Models for Real-World Health Care Data

- Observational Medical Outcomes Partnership
- Health Catalyst
- PCORnet[®]
- FDA Sentinel Initiative
- Health Care Systems Research Network

Compelling Questions: What Must We Address in the Years Ahead?

Readying for another pandemic is widely viewed as an imperative in light of the impact of COVID-19. Preparedness and surveillance have been relegated, but renewed investments in data, workforce, and materiel are essential at the state and federal level. Concurrently, further study and testing of how to activate and actualize the learning health system will yield widespread benefits and ensure that biomedical research successes reap their full potential. This could have the corollary benefit of invigorating and restoring the health care workforce, in that clinicians could see the more immediate benefits of applying knowledge at the point of care. Concerted focus on the basic infrastructure needs of neighborhoods and communities can spur engagement in health and health outcomes. Finally, thoughtful attention to the emergent field of data justice, coupled with scrutiny of embedded biases in artificial intelligence, are two of many needed steps in effectively using data to mitigate health inequity. Compelling questions may include:

- What should/will a learning health system look like to meet the needs in the next 5 years?
- What would be necessary to mount a coordinated and accelerated response to the next major public health challenge?
- What are the most effective approaches to dissemination and implementation of evidence, given the heterogeneity of U.S. health care?
- How can the wide range of data sources be leveraged most effectively to accelerate evidence generation and translation?

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Appendix B

SLIDE PRESENTATIONS FOR MARCH 15–16, 2021 MEETING



Hosted by the National Academy of Medicine and the Patient-**Centered Outcomes Research Institute**

> Share your thoughts! @theNAMedicine @PCORI



MATIONAL ACADEMY OF MEDICINE

Welcome & Introduction



Michael McGinnis National Academy of Medicine





Nakela Cook Patient-Centered Outcomes Research Institute



pcor

Neil Powe University of California, San Francisco

Agenda

Welcome, introductions & meeting overview	11-11:15 AM		
Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute Neil Powe, University of California, San Francisco			
Priorities on the Health Horizon: Overview Presentations	11:15-1:15 PM		
Rachel Hardeman, University of Minnesota Joshua Denny, National Institutes of Health David Muhlestein, Leavitt Partners Rainu Kaushal, Weill-Cornell School of Medicine			
Break	1:15-1:25 PM		

Agenda			
Stakeholder Perspectives on trends and opportunities	1:25-2:20 PM		
Karen DeSalvo, Google Gwen Darien, National Patient Advocacy Foundation Bruce Seigel, America's Essential Hospitals Austin Frakt, Boston VA Peter Embi, Indiana University School of Medicine			
Closing Remarks	2:20-2:30 PM		
Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute Neil Powe, University of California, San Francisco			
Adjourn	2:30 PM		

Priorities on the Health Horizon: Overview Presentations



Rachel Hardeman University of Minnesota School of Public Health



Joshua Denny National Institutes of Health All of Us Initiative



David Muhlestein Leavitt Partners



Rainu Kaushal Weill-Cornell School of Medicine

PCORI Priorities on the Health Horizon Social and Environmental Factors

Rachel R. Hardeman PhD, MPH Blue Cross Endowed Professor of Health and Racial Equity PI Measuring and Operationalizing Research to achieve Health Equity Lab Founding Director, Center for Antiracism Research for Health Equity



🥊 @MORhELab

🧭 @RRHDR

Fighting for America's Paradise

The only way to change the order, she thought, was not to do something differently, but to do a **different thing**. —Toni Morrison, Paradise



Goals for our 20 Minutes Together...

- To describe acute and longstanding health inequities that are caused or exacerbated by structural racism
- To understand how the conditions of daily life (social determinants) experienced by historically oppressed groups have their roots in structural racism and impact health and well being
- To offer insight into opportunities for improvement and transformation



80 | Priorities on the Health Horizon

Social Determinants of Health

In many ways, the current approach to the SDOH within medical education positions them as "facts to be known" rather than as "conditions to be challenged and changed." Educators talk about poverty but not oppression, race but not racism, sex but not sexism, and homosexuality but not homophobia.

2018, Sharma et al; Teaching the Social Determinants of Health: A Path to Equity or a Road to Nowhere?



Why do the social determinants matter for health?



Hardeman, Murphy et al. 2018





https://www.teenvogue.com/story/what-is-redlining-united-states

Structural Racism and Health Inequity



Even of Monstor

82 | Priorities on the Health Horizon



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🦅 @RRHDR

Figure 1				
Black People	e as a Share o	of COVID-19 Vac	cinations, Cas	es, Deaths an
Total Populat	ion, March 1, 2	2021		
Based on vaccinations	, cases, and deaths with	known race/ethnicity, amor	ng states reporting vaccin	ations by race/ethnicity
Click on the buttons be	yow to see data for the c	lifferent race/ethnicity arour	18'	
Black Hispanic A	sian White	, , , ,		
State	Percent of Vaccinations	Percent of Cases	Percent of Deaths	Percent of Total Population
Alabama	19%	29%	30%	27%
Alaska	1%	3%	3%	2%
Arizona	2%	4%	3%	4%
California	3%	4%	6%	5%
Colorado	3%	4%	3%	4%
Connecticut	4%	11%	12%	10%
Delaware	10%	24%	23%	22%
District of Columbia	26%	49%	76%	45%
Florida	7%	14%	16%	16%
Georgia	19%	32%	34%	31%
Illinois	8%	13%	18%	14%
Indiana	5%	8%	8%	9%
Iowa	1%	5%	2%	4%
Kentucky	4%	8%	9%	8%
Louisiana	23%	33%	39%	32%
Maine	196	6%	2%	1%
Maryland	17%	33%	35%	30%
Massachusetts	6%	8%	7%	7%
Michigan	7%	14%	23%	13%
Mississippi	25%	38%	40%	38%

PREPUBLICATION COPY—Uncorrected Proofs



White supremacy shaped America





Opportunities for improvement and transformation





🦅 @RRHDR

PREPUBLICATION COPY—Uncorrected Proofs

Personal Transformation





Structural Racism and Supporting Black Lives — The Role of Health Professionals

Rachel R. Hardeman, Ph.D., M.P.H., Eduardo M. Medina, M.D., M.P.H., and Katy B. Kozhimannil, Ph.D., M.P.A.



- Learn about, understand, and accept the United States' racist roots;
- Understand how racism has shaped our narrative about disparities;
- Define and name racism;
- Recognize racism, not just race;
- "Center at the margins"



Pund Black scientists kelly R. Stevens, et al.

Research Transformation

DEBATE-COMMENTARY	1156
Examining racism in health serv self-critique	ices research: A disciplinary
Racial disparities in health have existed in the United States for contaries. ¹ In 1899, WEB Du Bois noted the prevalence of poor health assess their senses, describing it as a superstant infector.	1 RACISM, WHITE SUPREMACY, AND HEALTH SERVICES RESEARCH
of ancietal curied inequality? Block Americans continue to have	Sturtured racion lies underwerk, all second and across or
substantially arrow health and denter life early towing the flat	It refers to the operations and institution of an array of
white countermarts. ¹³ Particularly in health services respects, ex-	namics. Namical rubust institutional and international
idence of black-white dissocities in health and health care costs.	reutinely advantase whites while producing cumulative and ch
have been acknowledged for decades. However, much of this	adverse outcomes for black people. ⁴ Structural racium encomp
work has been divorced from the social context of deeply seated	(a) history, which lies underneath the surface, providing the fo
racial oppression bead racised that has created it. This darger-	tion for white supremacy in this country, bit culture, which exit
ously incomplete view of disparities often fails to evoke racism as	around our everyday lives, providing the normalization and re-
the fundamental cause of these injustices. ⁴ By separating health	tion of racism; and ic) interconnected institutions and policies
disparities from racism, we full to recognize disparities as inequi-	key relationships and rules across society providing the legit
tes-that is avoidable injustices. Instead, we focus on individual	and reinforcements to maintain and perpetuate racium. ⁴ To pro-
differences rather than the systems and structures that uphold	antiracist research and to achieve health equity, we must ack
and replicate them.	edge the influence of white supremacist ideologies within our
Disciplinary self-critique, a tenet of public health critical race	plne. However, our traditional redions of white supremacy ise
pravis (PHCRP), helps a discipline shine a light on itself from	focused on hate groups and vulgie language rather than a cultur
within in order to understand how its norms may inadvortently	ideology born from the promise of black inforiority and false to
buttress inequities either within the discipline or in society at	of race as biological that have permeated the ways in which we
large." PHCRP also defines the term "outsiders within" as peo-	duct our research. As a result, a white racial frame-the overar
ple who are members of a field but often marginalized within it.	worldview that encompanies important racial ideas, terms, in
because of their social identity. We, the authors of this commen-	enotion and interpretation, and lens by which white suprem
tary, represent the outsiders within. We understand and appre-	perpetuated-then legitimizes structural racism by providing a
ciate the discipline of health services research, its strengths and	tive, belief system and worldview that upholds and sustains it.
visions. We care deeply about how health services research can	long-held belief systems drive the research questions we as
and should address health inequities and propel our discipline	nethods we employ and the interpretation of our research fits
toward more equilable realization of its measure to produce new	By interrugating 8, head on, we have everything to gain in the
knowledge about the structure, processes, and effects of health	tur race team equity and the production of antiracist resear
services for individuals and populations. This commentary will in-	A decipinary set-croque of eur.
terrepart the ways we as nearth services researchers pose our	
research questions, create methodological approaches, and inter-	1. NEWARK GROOM, Interofficiant rotions about race ship

- · Predominant notions about race shape framing of research questions
- Flawed methodology
- · Inaccurate interpretation of findings
- · Emancipation from the dominant frame

Health Systems Transformation

The NEW ENGLAND JOURNAL of MEDICINE
Perspective
Stolen Breaths Racket R Hademan, Ph.D., M.P.H., Edwards M. Medra, M.D., M.P.H., and Hen W. Boyd. M.D., M.P.H. To Minnessen, Hence Bolds: Americans account more thread hade page can- term of the Minnessen Account of the Control Minnessen Account of the Minnessen Account o

- Divest from racial health inequities.
- Desegregate the health care workforce.
- · Make "mastering the health effects of structural racism" a professional medical competency.
- · Mandate and measure equitable outcomes.
- Protect and serve

Hardeman, Rachel R, Karbeah J. "Examin services research65 Suppl 2 (2020): 777.

n Minnesota, where bl for 6% of the populati cases and 33% of Covi died at the hands of polic	The truth is black people can- not breathe because as many mourn George Hoyd, we also mourn Breonna Taylor and Tony McDade, and the nearly 1000 peo- nel who are killed by police such	
"Hease — I can't intefie."	In the wake of his public ese-	year, an outsized proportion of
He was a black man detained	cution, uprisings have ignited in	whom are black.



Policy Opportunities

RESEARCH ARTICLE | JANUARY 22 2021 Fighting for America's Paradise—the Struggle against Structural Resonance Tennore L Hadmana-Jones (Salardi M. Madra Janah het Neis Law 1970/R. Impediate Structure American Structure Bandard Yeller ¹ PG⁻ of Clar ⁴ Date ¹ Premissions

Abstract

Account in some in a fundamental cause of racial inequities in health in the United Bases. Shoutural raciant is manifested in inequility in the chimmel juicies synthesis de facto segregation in decision, health cause and hoating, and inefficient and departments where the backston, health cause the Backs people on terms and the segregation in the decision paid that Backs people on communities of cold factors in the decision tank continues of policity plant makes Black and Brown also a labelity, we are now in an upgreated moment on on bulk programs. The segregation is new administration which registrating states. The moment has corns for our rains to take all wayteme continu. And the advertes the animal end the pomping of the anisotic or good states. The moment has corns for our racings to take antipolicy must first the support full the source of the pomping of the anisotic on strongs. The oppershifts to create involvative and bulgeting stratifics. The notice of the anisotic network of the anisotic network of the anisotic network on the source and the source and the source and the source of the anisotic network of the source of the anisotic network of t

- Comprehensive Covid response
- White House Office of Racial Equity
- Universal Comprehensive Single Payer Healthcare
- Prioritize Policy that Supports the Social Determinants of Health
- Reparations

Hardeman R, Hardeman-Jones S,, Medina E. Fighting for America's Paradise. JHPPL 2021

Thank You!

Rachel R. Hardeman PhD, MPH hard0222@umn.edu RachelHardeman.com MORHELab.com

💓 @RRHDR



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Research Questions We Should be Asking

- Measurement and operationalization of structural racism
- How do we move from a simplified depiction of race/ethnicity, gender, and socioeconomic status as individual-level characteristics to one that more accurately interprets them as social constructs
- How can we prioritize larger, more diverse and representative population-based samples in our work?
- How do we better center at the margins? Get funding and research design into the hands of those closest to the pain...



Policy Opportunities

- Invest in the Social Determinants of Health
- Fund community based and Black (BIPOC) led organizations
- Grow and diversify the healthcare workforce
 - Medical Reparations
- Improve and mandate data collection and quality measures
- Support innovative care models & payment models led by historically oppressed communities
- Medicaid expansion
- Mandate anti-racism training

SCHOOL OF PUBLIC HEALTH UNIVERSITY OF MINNESOTA



All of Us Research Program Mission and Objectives



All of Us Research Program: Summary of Protocol and Status

Key elements:

- Goal: 1 million or more diverse participants
- Disease-agnostic, all health stages
- National launch May 6, 2018
- Current: >370k participants, >274k completed all initial steps
- Focus on diversity: >50% diverse race/ethnicity, >80% underrepresented in research
- Participants will get data back (genetics, EHR)
- •Longitudinal, recontactable



Enrollment Centers Encompass Traditional Academic Healthcare Centers and Non-Traditional Research Sites











Return of Participant Results Is An Important Part of *All of Us:* Genetic Return of Results

- Currently processing 4,500 Biosamples each week.
- As of March 8, 2021, the program has generated:
 - **37,414 genotyping results** for return of results
 - 17,571 whole genome sequencing results
 - 24,456 views of genetic ancestry results
 - 22,063 views of genetic trait results

97% of participants want to receive genetic results
(similar across all demographics)
>70% have viewed their results



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EHR Vendors and Data Quality: A Journey to Improved Interoperability





Bringing Researchers to Data Facilitates Collaboration





Impact of Precision Medicine on The Healthcare Continuum Example: Infectious disease





Power of Common Data Models

Vanderbilt	<pre>"first_drug_exposure AS- (- SELECT s1.person_id,- </pre>	
All of Us	<pre>"first_drug_exposure AS- (SELECT s1.person_id,. </pre>	42
Patrick Wu, PhD Defense),"¬	

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Precision Medicine in 2030: Seven Ways to Transform Healthcare

1. Huge, interoperable research cohorts providing diverse sampling of variability in genetics, environment, and lifestyle.

2.Improved diversity and inclusion in science in participants and researchers.

3. Routine use of clinical genomic testing to guide prevention, diagnosis, and therapy.

4.Big data and artificial intelligence applied to structured and increasingly, unstructured, information.

5.EHRs as a source for phenomic and genomic research. EHR-based genomics will rapidly outpace research applications. Most healthcare occurs outside healthcare centers, so EHRs will increasingly incorporate participant provided information.

6.Higher variety, higher resolution phenomics and environmental exposure data for both clinical and research use, including data linkages, more detailed sensor and wearable data, and precision nutrition.

 Privacy, participant trust, and returning value to participants, including focus on data security, transparency, and engagement.

Denny, Collins, Cell, in press

How Medicine and Technology Will Change By 2030

	Where we are today	Where we will be in 2030
Clinical applications		
Genomics for disease	Primarily limited to rare disease and select cancers.	Genomics is routine. Genetic causes and targeted therapies are discovered for many "common" diseases. Microbiome measures are routinely included.
Pharmacogenomics (PGx)	Common in cancer and within select applications of older medications at select sites.	Genome-aware EHRs make PGx easy and automatically update rules from central guidelines. New PGx associations discovered from clinical data.
Genomics for healthy individuals	In research, whole-genome sequencing and search for mutations in one of the ACMG59 genes, present in about 3% of people. Variant interpretation is hard.	ACMG59 grows to > 200, variant interpretation improved by huge, diverse sequenced populations. Cell-free DNA becomes a mainstay of cancer screening
EHRs	Episodic capture from healthcare without robust genomics support. EHR data is essentially not portable.	Genome- and device- enabled. Data can be easily moved between EHRs and to participant apps.
Environmental influences on health	Patient-reported habits and exposures	Geocode-based exposure linkage Real time monitoring of multiple environmental exposures Precision nutrition
Wearable sensors	Ad hoc use of activity monitors	Continuous monitoring of physical activity, sleep, metabolic parameters

Denny, Collins, Cell, in press

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Thank You!



OPTIMIZING VALUE

DAVID MUHLESTEIN, PHD JD CHIEF STRATEGY & CHIEF RESEARCH OFFICER @@DAVIDMUHLESTEIN DAVID.MUHLESTEIN@LEAVITTPARTNERS.COM

March 15, 2021













Continued Growth of Medical Care Average Difference Between Medical Inflation and Total Inflation 3.0% 2.5% 2.0% Average: 1.7% 1.5% 1.0% 0.5% 0.0% 1950s 1960s 1970s 1980s 1990s 2000s 2010+ Source: St. Louis Reserve, "Inflation in the healthcare industry vs. general CPI"



Economic Tension



Driver of Action



Impact of Value-Based Care



Medicare Shared Savings Program ACO Performance Over Time



Source: Gonzalez-Smith, Jonathan, Robert S. Saunders, William K. Bleser, David Muhlestein, and Mark B. McClellan. "The Medicare Shared Savings Program In 2019: Positive Results During Major Transitions And On The Eve Of A Pandemic." *Health Affairs Blog*, October 20, 2020. (doi:10.1377/hblog/2020/blo.834673/r/uil) and Medicare Encolment Dashboard https://www.cma.gov/research=statistics/add=system/statistics/2019-medicare-encolment-section





What is Value?





VS

See also Reinhardt, Uwe, "Priced Out" 2019

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Differing Approaches to Value Transformation



Change the

Options

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Differing Approaches to Value Transformation



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Progression of Provider Payment Arrangements



Shared Savings Pay For Performance (P4P) Pure Fee-For-Service Custow

Where Do We Want to Go?



Changing the Worldview

Capacity-Focused Approach Business model:

- 1. Identify the best-paid services
- 2. Build capacity for those services
- 3. Fill that capacity

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Patient-Needs Approach

Business model:

- 1. Identify patients' needs
- 2. Build low-priced services to fulfill needs
- 3. Prevent high-cost care



New Theory of Change in Value-Based Healthcare







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Rainu Kaushal, M.D., M.P.H Nanette L. Laitman Distinguished Professor Senior Associate Dean, Clinical Research Chair, Department Population Health Sciences Weill Cornell Medicine and NewYork Presbyterian

Weill Cornell Medicine

-NewYork-Presbyterian





Infrastructure for health and healthcare





INSIGHT 12M patients



Weill Cornell Medicine

INSIGHT

PCORnet



Weill Cornell Medicine

INSIGHT Clinical Research Network

PIPES

- Largest urban clinical datamart with 12m patients
- · Deep informatics expertise
- · Alignment with international data sharing efforts
- · Integration with clinical research infrastructures

PEOPLE

- · Effective and trusting alliances with CEOs, health system executives and clinicians
- Effective engagement of patients and community organizations
- Engagement of hundreds of researchers across 5 top AMCs with extensive clinical trial and health service expertise

<u>TRUST</u>

- · Clinical data sharing across competitive institutions
- · Commitment to supporting other people's research
- Learning health system: active improvement cycle

Weill Cornell Medicine

INSIGHT

Real World Data

Claims Data SDH Medicare: 3M patients · Patients with 9-digit zip codes and block · Medicaid: 2M patients level data 1199; 430K patients Linked to the American Community Survey data **Commercial Claims Data** Anthem Optum **Clinical Data** Humana 12 million unique patients Patient 300 million clinical encounters · Patient-reported outcomes · Patient generated data Over 2 billion lab values · Biospecimens INSIGHT **Weill Cornell Medicine**

🚓 pcornet

Stakeholder Engagement



Weill Cornell Medicine

300+ Engaged Projects

PCORnet Front Door

AD4PTABLE (Jones Hernandez) Antibildic and Obesity Study (Herman) Barainc Surgery Study (Schlund) IP Control (Pletcher) HRIV/IDS Research NWXSTED (Harvant) Parinson's and Osteoporosis PNDOS (Tailan) PREVENTABLE (Averander) PREVENTABLE (Averander) PREVENTABLE (Jours) RELIAIVCE Teleheard in COVID(Ancker)

Sample Federally Funded Studies

PCOL The Impact of Madical Health Homes on Patients with Diabetes - 52.25M identifying and Predicting Patients with Preventable High Utilization \$1.2 M HealthCore-Arthem Research Helwork (HCAR1) - 53.2M Preventing Tipping Points High Comparison (Patients - 57.3M Improving Netformin Utilization And Diabetes Control - 25M Predicting Early SQN Readmissions of CPF Patients - 326K COVID-19 Stolet and Secondary PCORE, Pregnancy and Delivery - 5160K COVID-19 Stolet and Secondary PCORE, Pregnancy and Delivery - 5160K Reform ChCS Enhancement Clarey (COVID-Specific) - 525M Patient-reported impact of COVID-19 Inteller-in-place policies - 55M Hist and Teiheadath Support Transitions Clarae amount CHP Heaters - 542M

Other Federal Sources

ERPC Care Enloyeds: In New Yon- SPOX Moding Social bench for Healthore Childrands in Depression - 540K National Surveillance Infrastructure for Priority Medical Devices - 52.25M Advancing Vederala Device France Surveillance Infrastructure - 51.1M DE Childronnetti Microscan Child Intel Houstones - 54.39M Pealiaric Anauliscon y Healthore Associated Infections - 51.30M Menial Technoliscon Vietnession vietnession - 67.90K Menial Intel Research Network - 50K

EHR-Based vs Population-Based CVD Risk Predictions - \$50K

The value of health system-based screening for SDoH - S2M Investigating poor prognosisalter being diagnosed with COVID-19 - S2M Incidence and prevalence of diabetes by type in young adults in NYC - S2.5K

Sample Locally Funded Studies

Racial Disparity in CKD - \$5K

Phenotype and Genotype Frequency Data in Diagnosing APS1 - \$25K Risk Modeling and Shared Decision Making for Post-Partum Depression Linking VA and non-VA Data to Study the Risk of Suicide in Chronic Pain Patients Public Health Surveillance

Immunomodulatory Medication Use and COVID-19 in Systemic Rheumatic Disease Investigating COVID-19 hotspots in NYC to create better predictive modeling. Risk prediction model for severe COVID outcomes among older patients - SSOK Baseline data on first presentation and outcomes to validate an Al prediction tool Inferdence multi-longetimes and example of CPUID-19, SSOK

Underlying medical conditions and severity of COVID-19 - \$10K Prevalence of Psychiatric Medication Prescriptions in COVID-19 Patient Outcomes COVID-19 in Pediatric Populations - \$10K

Mobile Stroke Units and spending, utilization, and outcomes - \$675K Telemedicine & Patient Loyalty, Healthcare Utilization and Spending - \$1.1M Community Tele-paramedicine randomized control trial - \$625K



Weill Cornell Medicine

The Health Horizon for the Next Five Years



Weill Cornell Medicine

Learning Health Systems



Weill Cornell Medicine

Thank you

Rainu Kaushal, M.D., M.P.H rak2007@med.cornell.edu





(1:15-1:25 pm ET)

For more information about the National Academy of Medicine's and PCORI's initiatives, please visit us at: nam.edu and pcori.org



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Stakeholder Perspectives on Trends and Opportunities



Google Health



Gwen Darien National Patient Advocacy Foundation



America's Essential Hospitals



Austin Frakt Boston's University School of Public Health



Peter Embi Indiana University School of Medicine

getheNAMedicine



Closing Remarks

Thank you for joining!

For more information about the National Academy of Medicine's and PCORI's initiatives, please visit us at: nam.edu and www.pcori.org

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Share your thoughts!





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Welcome & Day 1 Recap



Michael McGinnis National Academy of Medicine



Nakela Cook Patient-Centered Outcomes **Research Institute**



Neil Powe University of California, San Francisco

The second statement of medicine

Agenda

Welcome & Day 1 Recap	11-11:25 AM		
Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute Neil Powe, University of California, San Francisco			
Breakout Groups Discussions: Trends, Opportunities, and Priorities	11:25-1:15 PM		
Julia Adler-Milstein, University of California, San Francisco Technologies Group Facilitator Caroline Fichtenberg, University of California, San Francisco Social & Environmental Factors Group Facilitator Eric Larson, Kaiser Permanente Washington Optimizing Value Group Facilitator Risa Lavizzo-Mourey, University of Pennsylvania Infrastructure Group Facilitator			
Break	12:35-12:45 PM		

Agenda



Breakout Group Reports: Key Themes and Insights

Infrastructure Sarah Greene National Academy of Medicine

Technologies Kathleen Blake American Medical Association

Social & Environmental Factors Ivory Clarke National Academy of Medicine

> Optimizing Value Erin Holve DC Government

Infrastructure Breakout Group Report



Q1: Any additional topics/concepts to consider?

- How can we leverage the infrastructure created as a result of COVID-19 rather than revert to how things were pre-COVID?
 - Sustain administrative and contracting efficiencies throughout research process n
 - · Enhance learning networks and expand the apparatus we developed during COVID
 - Importance of virtualization changed how we work together
- How do we ensure translation and diffusion of evidence in a sustainable way, and reach broader audiences, especially for policy-relevant research?
 - Role of health literacy (writ large to include scientific & data literacy)
 - How information is transmitted, understood/misunderstood, (social scientists were trying to help people understand different approaches to receipt, processing and use of information, such as how public uses info to make vaccine choices

Infrastructure Breakout Group Report



Q2: Potential challenges, disruptors, opportunities & key trends on the horizon

- The way data, systems, and networks have been linked together have supported discovery process and potentially, these serve a collective disruption opportunity of learning from the new data sources, global experience with trials, e.g., UK RECOVERY
 - Ability to share/link data offers a vital opportunity to leverage our networks and ask better research questions.
 - Ability to aggregate data and get competitors to cooperate was a significant positive disruptor
- Combination of telemedicine and new sources of RWD (e.g., observable characteristics of virtual visits as a new source of fully understanding health
- Real world data is far more encompassing PROs, PGHD, etc. and how to link, curate, ensure quality and prepare RWD for population health is a huge disruptor.

Infrastructure Breakout Group Report



Q3: Major obstacles or challenges to advancing progress

- · Who is represented in the data, how it is used, and implicit biases
- Data access and is it equitable unto itself? Proprietary data and implications for its creation and use by technology companies. How do we ensure a level playing field with regard to access and use by private and public entities?
- Complexity of health and health care system creates challenges for patient engagement. Fatigue of having to navigate the system and utilize the available information.
- We've seen that the virtuous feedback loop of evidence to practice can be reduced and made much tighter, and yet we could slip back into the old timelines and lose the gains we made in the infrastructure space

Infrastructure Breakout Group Report



Q4: What else will it take to have a measurable & positive impact on health/care?

- We have to have a roadmap and we also need clarity about the destination what does a robust infrastructure look like and how can we ensure it?
 - PCORI can bring needed attention to this and invest in weak spots.

Technologies Breakout Group Report



Q1: Any additional topics/concepts to consider?

- Necessary foundations include trust, equitable solutions, broadband access, and adaptable infrastructures (care delivered in the home vs. inside the walls of a facility)
- There needs to be an emphasis on technology that resonates with patients and empowers them to be at the center of their health
- We need to value the evidence that is not what we traditionally consider rigorous
- Generating evidence by practice and using data in partnership with patients that is anchored more in outcomes in care

Technologies Breakout Group Report



Q2: Potential challenges, disruptors, opportunities & key trends on the horizon

- Challenges:
 - The lack of an open system that allows patients to be at the core of the research
 - A lack of time on the part of investigators and providers
 - The disconnect between systems (e.g., quality improvement professionals, researchers, public health, health systems)
- Opportunities:
 - · The ability of technology to surveil and make inferences on peoples' lives
 - Aligning incentives across agencies and revisiting the value of existing regulations

Technologies Breakout Group Report



Q3: Major obstacles or challenges to advancing progress

- New requirements will encounter resistance, unless the overall burden is immediately and measurably reduced
- A lack of standardized requirements and the application of community needs assessments with a focus on technology
- A resistance to bring patients to the table because of costs and relying solely on staff perspectives. Health systems tend to dictate the agenda.
- · Improving data quality and data context
 - Implicit bias

Technologies Breakout Group Report



Q4: What else will it take to have a measurable & positive impact on health/care?

- Gathering perspectives of patients in healthcare to help inform the changes in implementation and practice in telehealth, OpenNotes, digital tools, and wearables
- Research on the unique technology that providers use outside of traditional applications to make sure information is properly recorded
- Specific assessments that could help us better understand impact in current circumstances and inform meaningful measures
- Encourage activities that strengthen the connection between the Academy and health systems
- Develop partnerships with technology platforms that exist at scale to advance health

Social & Environmental Factors Breakout Group Report



Q1: Any additional topics/concepts to consider?

- Clarify that social and environmental factors is strongly linked to health equity, health justice
 - S&E factors include things like education, esp. early childhood, language/literacy, social cohesiveness, environmental racism, link back to redlining
- Social & environmental factors are clearly NOT solely the responsibility of health and health care institutions; they're cross-sectoral
- Patient-centeredness is critical: people don't experience their social needs in one silo, and health outcomes in another

Social & Environmental Factors Breakout Group Report



Q2: Potential challenges, disruptors, opportunities & key trends on the horizon

- Concern about the evidence: without good evidence, interventions that are not efficacious will be funded, and a lack of progress will lead to disinterest
- Cross-sectoral interest currently is promising, although there is concern about the durability of that interest
- Consider the burden on patient caregivers when thinking about chronic conditions, individual social needs.

Social & Environmental Factors Breakout Group Report



Q3: Major obstacles or challenges to advancing progress

- Question from the health care space: is it evidence-based? Need to develop evidence base for currently implemented programs, like food insecurity or implicit bias training). Research can inform practitioners about what they should, and should <u>not</u>, be doing.
 - Worry that if health care systems don't see impact after 5-10 yrs they will walk away
- Muddling the difference between goals and tactics: diversity is great, but it's a tactic. Goal is health, transforming and getting to just health.
Social & Environmental Factors Breakout Group Report



Q4: What else will it take to have a measurable & positive impact on health/care?

- Invite in those organizations that have been providing services to address SDOH—need incentives to broaden the family, better collaborate with existing institutions.
- Consider the impact of cost. Huge issue that thwarts PCOR if you can't consider opportunity cost, out of pocket, life cost.
- Need to deeply engage with all stakeholders, understand their needs.

Optimizing Value Breakout Group Report



Q1: Any additional topics/concepts to consider?

- Workable measures that *define* value, with data advancing these measures to fuel the journey
- Identifying best practices, to optimize patient value, with particular focus on alignment with spending
- Reimagining integration with the public health system (health in all policies); support for Medicaid

Optimizing Value Breakout Group Report



Q2: Potential challenges, disruptors, opportunities & key trends on the horizon

- COVID highlighted the following ("never waste a crisis"):
 - Heightened concept of "health" as a desired attribute of each individual (whole health)
 - Provider resilience re: organizationally capitated models (vs. commission models)
 - Patient heterogeneity recognition re: pathogens and treatments; precision medicine
 - Importance of a robust, prepared PubH infrastructure that "puts health in every policy"
 - Value placed on "taking responsibility for your own health" (re: masking, distancing, self care)
 - Health system's duty shifting from "delivering" health to "co-creating" and empowering health
- PCORI's mandate to study economic impact (on patients/SDOH)
 - What's the financial toxicity to patients and families?

Optimizing Value Breakout Group Report



Q3: Major obstacles or challenges to advancing progress

- Economic dependence on health and healthcare—largest netting business, and as such, lots of energy required to change (for profit to non). "How to lead your organization to success failure" if "success" means profits instead of health
 - Moving the focus to "health," vs. "price"
- The legacy chassis obscuring where investments should even go
- As healthcare consumes more of each dollar, funding is diminished for all other important social investment (e.g. education, housing)
 - This puts downward pressure on people's health via the social determinants
 - We must think of social determinants as the drivers, not just the external factors
- · Money spent on the preservation vs. the pursuit of health
- The transformation will create winners and losers-patients included
 - Although, there are winners and losers now as well

Optimizing Value Breakout Group Report



Q4: What else will it take to have a measurable & positive impact on health/care?

- Starting with "health" vs. "costs" is a transformative opportunity—change the narrative away from self interests, and towards a common good
- Value as a public health emergency
- What are the business models that can help providers/practices transition? (accounting for heterogeneity, and surrounding whole health)
- Opportunity to develop a balanced (matrixed) portfolio of research that analyzes both "value" and "burden" at both the individual and community level—in terms of concrete figures and strong research

Thank you for joining!

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Hosted by the National Academy of Medicine and the Patient-**Centered Outcomes Research Institute**

Meeting 2 – April 27th, 2021

Share your thoughts!





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Welcome & Introduction



Michael McGinnis National Academy of Medicine



Nakela Cook Patient-Centered Outcomes **Research Institute**



Neil Powe University of California, San Francisco

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NAM LEADERSHIP CONSORTIUM

Advancing the Learning Health System

A learning health system is one in which science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity-with best practices and discovery seamlessly embedded in the delivery process, individuals and families active participants in all elements, and new knowledge generated as an integral by-product of the delivery experience.

Leadership Consortium Charter 2006





focus:

COLLABORATIVE ACTION





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CORE ELEMENTS FOR EACH COLLABORATIVE

ORGANIZATIONAL NETWORKS

ANCHOR PRINCIPLES

KEY PROGRESS INDICATORS

COLLABORATIVE PROJECTS



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Agenda

Welcome, introductions & meeting overvie	ew 11-11:20 AM
Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Neil Powe, University of California, San Francisco	n Institute
Synopsis of first Priorities on the Health Horizon Convening	11:20-11:35 AM
Neil Powe, University of California, San Francisco	
Fireside Chat – Discussion of the Anchor Questions	11:35-12:15 PM
Consuelo Wilkins, MD, MSCI, Vanderbilt University Atul Butte, MD, PhD, University of California, San F	/ School of Medicine Francisco

Sachin Jain, MD, MBA, SCAN Group and Health Plan

Agenda

Break	12:15-12:25 PM
Stakeholder Perspectives on trends	12:25-1:25 PM
Summary of Group Discussion Insights	1:25-1:40 PM
Neil Powe, University of California, San Francisco	
Closing Remarks	1:40-1:55 PM
Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute	
Adjourn	1:55-2 PM

Fireside Chat: Discussion of the Anchor Questions



Consuelo Wilkins, MD, MSCI Vanderbilt University School of Medicine



Atul Butte, MD, PhD University of California, San Francisco



Sachin Jain, MD, MBA SCAN Group and Health Plan



Break 12:15-12:25 pm ET

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What Will It Take? Group Discussion



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Group Discussion: Anchor Question 1

What would it take to advance the patient-centered learning system, including changes to our infrastructure, engagement and technologies?

- How would the health care, health promotion and public health infrastructure need to change?
- How would we think differently about engagement of patients, clinicians, communities and other stakeholders?
- What is PCORI's role in maximizing the positive and equitable impact of technologies (precision medicine, apps, devices, etc.), and what evidence gaps can PCORI fill?

Group Discussion: Anchor Question 2

What would it take for PCORI to fully utilize its research strategies and core competencies to expand the concept of patient-centered value in health and health care?

- What are the opportunities for <u>evidence generation</u> that would support this conception of patient-centered value?
- How could PCORI drive rapid, innovative comparative effectiveness research on new care delivery models (hospital @home, telehealth, etc.) and illuminate the effects of new delivery models on value in health care?
- Who are key partners, including non-traditional partners for PCORI here?



Summary of Group Discussion Insights



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Closing Remarks

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Appendix C

AGENDA, MARCH 15-16, 2021 MEETING

PRIORITIES ON THE HEALTH HORIZON

A Virtual Meeting to Inform PCORI's Strategic Plan

March 15, 2021, 11:00am–2:30pm March 16, 2021, 11:00am–2:15pm

MEETING GOAL: Engage PCORI stakeholders in discussion of current and emerging priorities on the health and health care horizon, and summarize perspectives for PCORI's strategic planning efforts.

MEETING OBJECTIVES:

- Present essential perspectives related to current and emerging priorities, trends, and opportunities on the horizon in the health and health care landscape
- Discuss stakeholders' thoughts on and priorities for these emergent topics for PCORI's mission

Day 1 – March 15, 2021

11:00 am Day 1: Welcome, Introductions, and Meeting Overview

Welcome from the National Academy of Medicine and PCORI

Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute Opening remarks and meeting overview by Meeting Chair

Neil Powe, University of California, San Francisco

11:15 am Priorities on the Health Horizon: Overview Presentations

This session will describe several key issues shaping the future of health and health care, including the ways in which each topic affects or is affected by the continuum of care. The presentations and discussion will impart opportunities, knowledge gaps and challenges as attendees consider priorities for health in the next 5-10 years.

Rachel Hardeman, University of Minnesota School of Public Health Topic: Social and Environmental Factors

Joshua Denny, National Institutes of Health All of Us Initiative Topic: Technologies

David Muhlestein, Leavitt Partners Topic: Optimizing Value

Rainu Kaushal, Weill Cornell School of Medicine Topic: Infrastructure

1:15 pm Break

1:25 pm Stakeholder Perspectives on Trends and Opportunities

Stakeholder representatives will share reactions to the presentations, including compelling trends; challenges; and other insights as they relate to patients/caregivers, clinicians, payers, policymakers and others

Karen DeSalvo, Google Health
Gwen Darien, National Patient Advocate Foundation
Bruce Siegel, America's Essential Hospitals
Austin Frakt, Boston University School of Public Health
Peter Embi, Indiana University School of Medicine

Reactors' perspectives will be followed by a facilitated to identify critical issues and questions that can inform the Day 2 breakout group discussions.

Neil Powe, University of California, San Francisco

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2:20 pm Closing Remarks in Preparation for Day 2

Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute

2:30 pm Adjourn

Day 2 - March 16, 2021

11:00 am Welcoming Remarks and Day 1 Review

Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute Neil Powe, University of California, San Francisco

11:15 am Breakout Groups Discussions: Trends, Opportunities, and Priorities for Each Topic

Groups will discuss a set of questions to encourage blue sky thinking about optimized or transformed health and health care, leveraging key trends and emergent areas discussed in the opening presentations.

Facilitators:

Julia Adler-Milstein, University of California, San Francisco: *Technologies*

Caroline Lichtenberg, University of California, San Francisco: *Social and Environmental Factors*

Eric Larson, Kaiser Permanente Washington: *Optimizing Value* Risa Lavizzo-Mourey, University of Pennsylvania: *Infrastructure*

Guiding Questions for Breakout Group Discussions:

- Thinking about the four topics presented on day one, are there additional concepts, topics, or key trends to consider?
- What are the potential disruptors and opportunities on the horizon in this topic area?
- What are the major challenges and obstacles to advancing progress related to this topic?
- What (else) would it take for this topic to have a measurable and positive impact on health and health care in the next 5 years?

1:15 pm Break

1:45 pm Convene for Breakout Group Reports: Key Themes and Insights

A brief summary of the Day 1 presentations and reactions will be provided

Neil Powe, University of California, San Francisco

Each breakout group will share key themes and insights from its discussions

Infrastructure Breakout Group Report Technologies Breakout Group Report Social and Environmental Factors Group Report Optimizing Value Group Report

A brief facilitated discussion will offer an opportunity to comment on breakout group reports, and invite each participant to identify one challenge or priority that would enable people to achieve their best health

Neil Powe, University of California, San Francisco

2:00 pm Reflections, Next Steps, and Closing Remarks

Concluding observations and insights will be offered, along with final thanks to all invited speakers and participants.

Michael McGinnis, National Academy of Medicine Sharon Levine, Vice Chairperson, PCORI Board of Governors

2:15 pm Adjourn

Appendix D

AGENDA FOR APRIL 27, 2021 MEETING

PRIORITIES ON THE HEALTH HORIZON

Informing PCORI's Strategic Plan

Meeting 2: April 27, 2021—Virtual Meeting

MEETING SERIES GOAL: Engage PCORI stakeholders in discussion of current and emerging priorities on the health and health care horizon, and summarize perspectives for PCORI's strategic planning efforts.

MEETING 2 OBJECTIVE: Discuss 2 compelling topics generated during the first meeting in March 2021:

- What will it take to create a patient-centered learning health system (with respect to infrastructure, technologies, and engagement)?
- How can PCORI use its research strategies, unique role, and activities to improve patient experience, outcomes, and value in health and health care?

Agenda at a Glance

11:00–11:20 am	Welcome, Framing, and Introductions
	(Michael McGinnis, Nakela Cook)

11:20–11:35 amSynopsis of First PCORI Priorities on the Health
Horizon Meeting (Neil Powe, Chair)

11:35 am– 12:15 pm	 Fireside Chat—Discussion of the Anchor Questions: Neil Powe (moderator) Consuelo Wilkins, MD, MSCI Atul Butte, MD, PhD Sachin Jain, MD, MBA
12:15–12:25 pm	Break
12:25–1:25 pm	 Facilitated Group Discussion: What would it take to advance the patient-centered learning system, including changes to our infrastructure, engagement, and technologies? What would it take for PCORI to fully utilize its research strategies, unique mission, and core activities to expand the concept of patient-centered value in health and health care?
1:25–1:40 pm	Recap/Summarize Key Insights (Neil Powe)
1:40–1:55 pm	Concluding Remarks/Wrap-Up (Nakela Cook, Michael McGinnis)
1:55–2:00 pm	Adjourn
Detailed Agenda	

11:00 am Day 1: Welcome, Introductions, and Meeting Overview

Welcome from the National Academy of Medicine and PCORI

Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute

Chair's opening remarks and meeting overview

Neil Powe, University of California, San Francisco

11:10 am Introductions

- 11:20 am Review of the First Priorities on the Health Horizon Meeting Neil Powe, University of California, San Francisco
- 11:30 am Fireside Chat: How can we realize a patient-centered learning health system, underpinned by health equity, and what is PCORI's unique role as we consider ways to improve patient experience, outcomes, and value in health and health care?
 - Neil Powe, University of California, San Francisco (moderator)
 - Consuelo Wilkins, MD, MSCI, Vanderbilt University School of Medicine
 - Atul Butte, MD, PhD, University of California, San Francisco
 - Sachin Jain, MD, MBA, SCAN Group and Health Plan
- 12:15 pm Break
- 12:25 pm What Will It Take? Group Discussion: The aspiration of a learning health system is predicated on use of representative clinical data and research evidence for better outcomes and more effective, efficient, and equitable care. Considering PCORI's mission and mandate to conduct patient-centered comparative effectiveness research, the group is invited to consider two compelling questions as described below.
 - 1. What would it take to advance the patient-centered learning system, including changes to our infrastructure, engagement and technologies?
 - How would the health care, health promotion, and public health infrastructure need to change?
 - How would we think differently about engagement of patients, clinicians, communities, and other stakeholders?
 - What is PCORI's role in maximizing the positive and equitable impact of technologies (precision medicine, apps, devices, etc.), and what evidence gaps can PCORI fill?

- 2. Thinking about PCORI's mission and mandate, what would it take for PCORI to fully utilize its research strategies, unique mission, and core activities to expand the concept of patient-centered value in health and health care?
 - What are the opportunities for evidence generation that would support this conception of patient-centered value?
 - How could PCORI drive rapid, innovative comparative effectiveness research on new care delivery models (hospital@home, telehealth, etc.) and illuminate the effects of new delivery models on value in health care?
 - Who are key partners, including nontraditional partners, for PCORI here?
- 1:25 pm Summary of Group Discussion Insights Neil Powe, University of California, San Francisco
- 1:40 pm Next Steps and Concluding Remarks Michael McGinnis, National Academy of Medicine Nakela Cook, Patient-Centered Outcomes Research Institute
- 1:55 pm Adjourn

Appendix E

PRESENTER AND FACILITATOR BIOGRAPHIES FOR MARCH 15–16, 2021 MEETING

Priorities on the Health Horizon: Informing PCORI's Strategic Plan March 15–16, 2021 Zoom Meeting

PRESENTER AND FACILITATOR BIOGRAPHIES

Julia Adler-Milstein, Ph.D., is a Professor of Medicine and the Director of the Center for Clinical Informatics and Improvement Research (CLIIR). Dr. Adler-



Milstein is a leading researcher in health information technology policy, with a specific focus on electronic health records (EHRs) and interoperability. She has examined policies and organizational strategies that enable effective use of electronic health records and promote interoperability. She is also an expert in EHR audit log data and its application to studying clinician behavior. Her research—used by researchers, health systems, and policy makers identifies obstacles to progress and ways to overcome them. Dr. Adler-Milstein holds a Ph.D. in health policy from Harvard University and spent 6 years on the faculty at the University of Michigan

prior to joining the University of California, San Francisco, as a Professor in the Department of Medicine and the inaugural Director of the Center for Clinical Informatics and Improvement Research. Nakela Cook, M.D., M.P.H., is the Executive Director at the Patient-Centered Outcomes Research Institute (PCORI). She is a cardiologist and health services



researcher with a distinguished career leading key scientific initiatives engaging patients, clinicians, and other health care stakeholders at one of the nation's largest public health research funders. Dr. Cook leads PCORI's research, dissemination and implementation, and engagement work as the organization enters its second decade of service to the nation. She also provides strategic and dayto-day oversight of ongoing programs as well as new initiatives designed to create a health care system that is more efficient, effective, and patient centered. Throughout her career, Dr. Cook has worked to enhance diversity and equity in research

and care delivery and been a leader in efforts to reduce disparities in health access and outcomes. She has received numerous awards for her excellence in clinical teaching and mentorship as well as her leadership of complex scientific initiatives and programs.

Gwen Darien is the Executive Vice President for Patient Advocacy and Engagement at the National Patient Advocate Foundation (NPAF). As the Executive



Vice President for patient advocacy and engagement, Ms. Darien leads programs that link patient advocate foundations' patient service programs to NPAF initiatives, with the goal of improving access to affordable, equitable quality health care. As a three-time cancer survivor herself, Ms. Darien came into cancer advocacy expressly to change the experiences and outcomes for the patients who came after her and to change the public dialogue about cancer and other life-threatening illnesses. With these goals in mind, in 2005 she started the first stand-alone advocacy entity in a professional cancer research organization at the American

Association for Cancer Research. In every role she has served in, Ms. Darien championed placing patients at the center of health system change, whether it is for research, public policy, or direct services.

Joshua Denny, M.D., M.S., is the Chief Executive Officer of the National Institutes of Health's (NIH's) All of Us Research Program. As a physician scien-



tist, Dr. Denny is deeply committed to improving patient care through the advancement of precision medicine. Before joining NIH, Dr. Denny was a Professor of biomedical informatics and medicine, the Director of the Center for Precision Medicine, and the Vice President for Personalized Medicine at Vanderbilt University Medical Center (VUMC). In his roles at VUMC, he was both a practicing internist and a researcher. His research interests include use of electronic health records and genomics to better understand disease and drug response. He also led efforts implementing precision medicine to improve patient outcomes. He is an elected member of the National Academy

of Medicine, the American Society for Clinical Investigation, and the American College of Medical Informatics.

Karen DeSalvo, M.D., M.P.H., M.Sc., is the Chief Health Officer at Google Health. She is also an Adjunct Professor of medicine and population health at



The University of Texas at Austin Dell Medical School and co-convenes the National Alliance to Impact the Social Determinants of Health. She is a physician executive working at the intersection of medicine, public health, and information technology to improve the health of all people with a focus on catalyzing pragmatic solutions to address all the social determinants of health. She serves on the Medicare Payment Advisory Commission and is on the Board of Directors for Welltower and previously served on the Board of Humana. She is the President of the Society of General Internal Medicine and the Honorary Vice President,

United States, for the American Public Health Association.

Peter J. Embí, M.D., M.S., FACP, FACMI, FAMIA, FIAHSI, is an internationally recognized researcher, educator, and leader in the field of clinical and



translational research informatics, with numerous peer-reviewed publications and presentations describing his innovations in the field. Dr. Embí serves as the President and the Chief Executive Officer of the Regenstrief Institute, and he holds related leadership roles at Indiana University (IU) and the IU Health System. He previously served in various leadership positions at The Ohio State University (OSU), including the Interim Chair of Biomedical Informatics, the Informatics Director of the OSU Center for Clinical and Translational Science, and the Chief Research Information Officer at the OSU Wexner Medical Center.

Caroline Fichtenberg, Ph.D., is the Managing Director of the Social Interventions Research and Evaluation Network and a Research Scientist in the



Department of Family and Community Medicine at the University of California, San Francisco. In these roles, she leads efforts to conduct, catalyze, and disseminate high quality research on health sector strategies to reduce health inequities by addressing social determinants of health. She brings to these positions more than a decade of experience working to improve health and economic outcomes for America's most vulnerable families, including 7 years working on national efforts in Washington, DC. **Austin Frakt, Ph.D.,** is a Health Economist and the Director of the Partnered Evidence-based Policy Resource Center at the Boston VA Healthcare System. He



is also a Professor of health law, policy, and management with the Boston University School of Public Health and a Senior Research Scientist with the Department of Health Policy and Management at the Harvard T.H. Chan School of Public Health. Dr. Frakt is the Editor-in-Chief of *Health Services Research* and serves on the editorial board of the *American Journal of Managed Care*. He is also an Editor-in-Chief and a primary author of the evidence-based health policy blog The Incidental Economist, a regular contributor on health policy topics to *The New York Times*' The Upshot, and has been a contributor to the JAMA Health Forum. Dr.

Frakt has conducted research studies funded by the Department of Veterans Affairs, the Robert Wood Johnson Foundation, The Commonwealth Fund, the Laura and John Arnold Foundation, and the Agency for Healthcare Research and Quality.

Rachel Hardeman, Ph.D., M.P.H., is a reproductive health equity researcher whose program of research applies the tools of population health science and



health services research to elucidate a critical and complex determinant of health inequity—racism. Dr. Hardeman leverages the frameworks of critical race theory and reproductive justice to inform her equity-centered work which aims to build the empirical evidence of racism's impact on health particularly for Black birthing people and their babies. Her work also examines the potential mental health impacts for Black birthing people when living in a community that has experienced the killing of an unarmed Black person by police. Dr. Hardeman is the principal investigator of MORhELab, which explores and defines ways

to measure structural racism for the purposes of empirical, quantitative investigation. Published in journals such as the *New England Journal of Medicine* and the *American Journal of Public Health*, Dr. Hardeman's research has elicited important conversations on the topics of culturally-centered care, police brutality and structural racism as a fundamental cause of health inequities. Her overarching goal is to contribute to a body of knowledge that links structural racism to health in a tangible way, identifies opportunities for intervention, and dismantles the systems, structures, and institutions that allow inequities to persist.

Rainu Kaushal, M.D., is a distinguished health services researcher, information scientist, and health care leader who serves as the Senior Associate Dean



for Clinical Research at Weill Cornell Medicine. She heads the Office of the Senior Associate Dean for Clinical Research, managing the growth and expansion of clinical research across the institution. Dr. Kaushal has led Weill Cornell Medicine's clinical research enterprise, driving the experimental application and comparative investigations of new medicines, technologies, interventions and health care delivery models to patients. Dr. Kaushal has also led an enterprise that harnesses the research faculty's expertise in specialized fields such as clinical trials, health informatics, health services research, epidemiology, and precision medicine to

propel the development and implementation of novel therapeutics.

Eric B. Larson, M.D., M.P.H., is a Senior Investigator at Kaiser Permanente Washington Health Research Institute. A general internist, Dr. Larson is a national



leader in geriatrics, health services, and clinical research and has been an elected member of the National Academy of Medicine since 2007. He pursues an array of research, ranging from clinical interests such as Alzheimer's disease and genomics to health services research involving technology assessment, cost-effectiveness analysis, learning health systems, and quality improvement. His research on aging includes a longstanding collaboration between Kaiser Permanente Washington and the University of Washington (UW) called the Adult Changes in Thought (ACT) study. With colleagues from Duke University and Harvard

University, Dr. Larson established and now helps lead the National Institutes of Health's (NIH's) Common Fund's Health Care Systems Research Collaboratory. The Collaboratory sponsors pragmatic clinical trials and aims to improve the way clinical trials are conducted so that patients and care providers have access to the best available clinical evidence for decision making.

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Risa Lavizzo-Mourey, M.D., M.B.A., is President Emerita and the former Chief Executive Officer of the Robert Wood Johnson Foundation (RWJF), a posi-



tion she held for nearly 15 years. During her tenure at RWJF, Dr. Lavizzo-Mourey spearheaded bold health initiatives such as creating healthier, more equitable communities; strengthening the integration of health systems and services; and ensuring every child in the United States has the opportunity to grow up at a healthy weight. This work culminated in the Foundation's vision of building a Culture of Health enabling everyone in America to live longer, healthier lives. A specialist in geriatrics, Dr. Lavizzo-Mourey came to the Foundation from the University of Pennsylvania, where she served as the Sylvan Eisman Professor of Medicine and

Health Care Systems. She also directed Penn's Institute on Aging and was the Chief of Geriatric Medicine at the University of Pennsylvania's School of Medicine. She is a member of the National Academy of Medicine, the American Academy of Arts & Sciences, the American Philosophical Society, and a former member of the President's Council for Fitness, Sports and Nutrition. She currently serves on the Smithsonian Institution Board of Regents and several other boards of directors.

Sharon Levine, M.D., is the Associate Executive Director for The Permanente Medical Group of Northern California; a large multi-specialty group practice in



Oakland, California, within Kaiser Permanente's integrated delivery system. A board-certified pediatrician, she has held multiple leadership roles with this group practice including the Chief of Pediatrics. She is an Adjunct Associate for the Center for Health Policy/Center for Primary Care and Outcomes Research at Stanford University and is also a board member of the Reagan-Udall Foundation, Integrated Healthcare Association, the Public Health Institute of California, and the California Medical Board. Dr. Levine has been a member of the Patient-Centered Outcomes Research Institute Board since 2010 and has been serving as its Vice Chairperson since September 2019. Michael McGinnis, M.D., M.A., M.P.P., is a physician and epidemiologist, serves at the National Academy of Medicine (NAM) as the Senior Scholar, the



Leonard D. Schaeffer Executive Officer, the Executive Director of the Leadership Consortium for a Value & Science- Driven Health System, and the NAM Learning Health System Initiative. Previously, Dr. McGinnis was the Senior Vice President and Head of the Health Group at the Robert Wood Johnson Foundation (1999–2005). Before that, he served as the Assistant Surgeon General and the Deputy Assistant Secretary for Health at the Department of Health and Human Services, with continuous leadership responsibility from 1977 to 1995 for federal activities in disease prevention and health promotion, a tenure unusual

for political and policy posts. Key programs developed and launched at his initiative include the Healthy People national goals and objectives, the Dietary Guidelines for Americans, and the U.S. Preventive Services Task Force, each still ongoing. Internationally, he served in India as the state director for the World Health Organization Smallpox Eradication Program (1974–1975), and in Bosnia as the Chair of the World Bank/European Commission Task Force for Reconstruction in Health and Human Services (1995–1996). Dr. McGinnis's scientific interests focus on population health and the determinants of health, his publications include approximately 200 articles and more than 20 edited books, and his various national recognitions include the Public Health Distinguished Service Award (1994), the Health Leader of the Year Award (1997), the Public Health Hero Award (2013), the Fries Prize for Health Improvement (2018), and election as a member of the National Academy of Medicine (1999), and a Fellow of the American College of Epidemiology and the American Association for the Advancement of Science. David Muhlestein, Ph.D., J.D., is the Chief Strategy and the Chief Research Officer for Leavitt Partners. He is responsible for the firm's strategic planning



and leads Leavitt Partners-directed research. Dr. Muhlestein's research and expertise centers on health care payment and delivery transformation, understanding health care markets, and evaluating how the broader health care system is changing. He is a self-identified data nerd and regularly speaks and writes about health care system evolution. Additionally, Dr. Muhlestein is a Visiting Policy Fellow at the Margolis Center for Health Policy at Duke University, an Adjunct Assistant Professor at The Ohio State University College of Public Health and a Visiting Fellow at the Accountable Care Learning Collaborative.

Neil Powe, M.D., M.P.H., M.B.A., serves as the leader of the University of California, San Francisco, Medicine Service at the Priscilla Chan and Mark Zuck-



erberg San Francisco General Hospital, a leading medicine department in a public hospital with strong basic, clinical, and health services research programs focused on major diseases affecting diverse patients locally, nationally and globally. His interests are in improving discovery, education, and clinical practice in medicine; making academic organizations function better; enhancing scholarship and multidisciplinary collaboration; and developing future talent and leadership in the health professions. His primary intellectual pursuits involve kidney disease patient-oriented research, epidemiology, and outcomes and effec-

tiveness research. His research unites medicine and public health with the goals of saving and improving quality of human lives. It involves the knowledge of fundamental discoveries in biology and clinical medicine to advance the health of patients and populations affected by kidney disease. Bruce Siegel, M.D., M.P.H., is the President and the Chief Executive Officer of America's Essential Hospitals (AEH). With an extensive background in health



care management, policy, and public health, Dr. Siegel has the blend of experience necessary to lead AEH and its members through the changing health care landscape and into a sustainable future. Since joining AEH in 2010, Dr. Siegel has guided the association toward realizing its strategic vision of advancing the work of hospitals committed to ensuring access to care and optimal health for America's most vulnerable people. He has helped shape the association's work in advocacy, member support, and quality. Under his leadership, AEH established a federally funded, national network of hospitals that improved patient safety and reduced

care disparities by averting more than 4,000 harm events and \$40 million in costs. In 2013, Dr. Siegel led the association in a strategic rebranding to better reflect the common purpose of its more than 320 members: to serve all people and communities by providing essential services and the best care possible. The association's new name preserves the sense of accountability central to its legacy and speaks to the essential services its members provide to communities across the country.

Appendix F

PRESENTER AND FACILITATOR BIOGRAPHIES FOR APRIL 27, 2021 MEETING

Priorities on the Health Horizon: Informing PCORI's Strategic Plan April 27, 2021 Zoom Meeting

PRESENTER AND FACILITATOR BIOGRAPHIES

Atul Butte, M.D., Ph.D., is a Professor and the Director of the University of California, San Francisco's Institute for Computational Health Sciences. He is a



former Professor of pediatrics and genetics, and by courtesy, medicine, pathology, and computer science, at Stanford University and Lucile Packard Children's Hospital. Dr. Butte is the Chief of the new Division of Systems Medicine at Stanford. Dr. Butte is also a founder of three companies: Personalis, providing clinical interpretation of whole genome sequences; Carmenta, discovering diagnostics for pregnancy complications; and NuMedii, finding new uses for drugs through open molecular data. Dr. Butte has authored more than 160 publications, with research repeatedly featured in *Wired* Magazine, in *The NewYork Times*

Science Times, and the International Herald Tribune, The Wall Street Journal, San Jose Mercury News, and the San Francisco Chronicle.

Nakela Cook, M.D., M.P.H., is the Executive Director at the Patient-Centered Outcomes Research Institute (PCORI). She is a cardiologist and health services



researcher with a distinguished career leading key scientific initiatives engaging patients, clinicians, and other health care stakeholders at one of the nation's largest public health research funders. Dr. Cook leads PCORI's research, dissemination and implementation, and engagement work as the organization enters its second decade of service to the nation. She also provides strategic and day-to-day oversight of ongoing programs as well as new initiatives designed to create a health care system that is more efficient, effective, and patient centered. Throughout her career, Dr. Cook has worked to enhance diversity and equity in research and care

delivery and been a leader in efforts to reduce disparities in health access and outcomes. She has received numerous awards for her excellence in clinical teaching and mentorship as well as her leadership of complex scientific initiatives and programs.

Sachin H. Jain, M.D., M.B.A., is the President and the Chief Executive Officer (CEO) of SCAN Group and Health Plan, where he is charged with lead-



ing the organization's growth, diversification, and emerging efforts to reduce healthcare disparities. SCAN's revenues top \$3.4 billion and the organization serves 220,000 patients. Previously, Dr. Jain was the President and the CEO of CareMore and Aspire Health. He pioneered the first clinical program in the world focused on social isolation. Dr. Jain is also an Adjunct Professor of medicine at the Stanford University School of Medicine and a contributor at *Forbes*. Prior to joining CareMore, Dr. Jain was the global Chief Medical Information and Innovation Officer at Merck & Co. He contemporaneously served as an attending physician

at the Boston VA Boston Medical Center and a member of faculties at Harvard Medical School and Harvard Business School. From 2009–2011, Dr. Jain worked in leadership roles at the Department of Health and Human Services, where he was the Senior Advisor to the Administrator of the Centers for Medicare & Medicaid Services.

Michael McGinnis, M.D., M.A., M.P.P., is a physician and epidemiologist, serves at the National Academy of Medicine (NAM) as the Senior Scholar, the



Leonard D. Schaeffer Executive Officer, the Executive Director of the Leadership Consortium for a Value & Science- Driven Health System, and the NAM Learning Health System Initiative. Previously, Dr. McGinnis was the Senior Vice President and Head of the Health Group at the Robert Wood Johnson Foundation (1999–2005). Before that, he served as the Assistant Surgeon General and the Deputy Assistant Secretary for Health at the Department of Health and Human Services, with continuous leadership responsibility from 1977 to 1995 for federal activities in disease prevention and health promotion, a tenure unusual

for political and policy posts. Key programs developed and launched at his initiative include the Healthy People national goals and objectives, the Dietary Guidelines for Americans, and the U.S. Preventive Services Task Force, each still ongoing. Internationally, he served in India as the state director for the World Health Organization Smallpox Eradication Program (1974–1975), and in Bosnia as the Chair of the World Bank/European Commission Task Force for Reconstruction in Health and Human Services (1995–1996). Dr. McGinnis's scientific interests focus on population health and the determinants of health, his publications include approximately 200 articles and more than 20 edited books, and his various national recognitions include the Public Health Distinguished Service Award (1994), the Health Leader of the Year Award (1997), the Public Health Hero Award (2013), the Fries Prize for Health Improvement (2018), and election as a member of the National Academy of Medicine (1999), and a Fellow of the American College of Epidemiology and the American Association for the Advancement of Science. Neil Powe, M.D., M.P.H., M.B.A., serves as the leader of the University of California, San Francisco, Medicine Service at the Priscilla Chan and Mark



Zuckerberg San Francisco General Hospital, a leading medicine department in a public hospital with strong basic, clinical, and health services research programs focused on major diseases affecting diverse patients locally, nationally and globally. His interests are in improving discovery, education, and clinical practice in medicine; making academic organizations function better; enhancing scholarship and multidisciplinary collaboration; and developing future talent and leadership in the health professions. His primary intellectual pursuits involve kidney disease patient-oriented research, epidemiology, and outcomes and effec-

tiveness research. His research unites medicine and public health with the goals of saving and improving quality of human lives. It involves the knowledge of fundamental discoveries in biology and clinical medicine to advance the health of patients and populations affected by kidney disease.

Consuelo H. Wilkins, M.D., M.S.C.I., is the Executive Director of the Meharry-Vanderbilt Alliance and an Associate Professor of medicine at both



the Vanderbilt University Medical Center and Meharry Medical College. Dr. Wilkins is a clinical investigator and an engagement researcher who is an Associate Director of the Vanderbilt Institute for Clinical and Translational Science, where she oversees programs in community engagement and team science. Dr. Wilkins is currently a Principal Investigator of the Vanderbilt-Miami-Meharry Center of Excellence in Precision Medicine and Population Health, which focuses on decreasing disparities among African Americans and Latinos using precision medicine; and the Vanderbilt Recruitment Innovation Center, a national center

dedicated to enhancing recruitment and retention in clinical trials. She is widely recognized for her innovative work developing and testing methods and tools to engage patients and communities in research and was recently named the Director of the Engagement Core of the All of Us Research Program, a national precision medicine project which will enroll a million or more participants.

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Appendix G

PARTICIPANTS FOR MARCH 15-16, 2021 MEETING

PRIORITIES ON THE HEALTH HORIZON: INFORMING PCORI'S STRATEGIC PLAN MARCH 15–16, 2021

Presenters

Rachel Hardeman, Ph.D., M.P.H.—Social and Environmental Factors Associate Professor, University of Michigan School of Public Health

Joshua Denny, M.D., M.P.H.—*Technologies* Chief Executive Officer, National Institutes of Health All of Us Research Program

David Muhlestein, Ph.D., J.D.—*Optimizing Value* Chief Strategy and Chief Research Officer, Leavitt Partners

Rainu Kaushal, M.D., M.P.H.—*Infrastructure* Senior Associate Dean of Clinical Research, Chair, Department of Population Health Sciences, Weill Cornell

Reactor Panel

Karen DeSalvo, M.D., M.P.H., M.Sc. Chief Health Officer, Google Health

Gwen Darien

Executive Vice President for Patient Advocacy and Engagement, National Patient Advocate Foundation

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Bruce Siegel, M.D., M.P.H.

President and Chief Executive Officer, America's Essential Hospitals

Austin Frakt, Ph.D.

Editor-in-Chief, Health Services Research; Director, Partnered Evidence-Based Policy Resource Center, Boston VA

Peter Embi, M.D., M.S., FACP, FACMI, FAMIA, FIAHSI

President and Chief Executive Officer, Regenstrief Institute, Professor of Medicine and Associate Dean, Indiana University School of Medicine

Breakout Group Facilitators

Caroline Fichtenberg, Ph.D.—Social and Environmental Breakout Group Managing Director, Social Interventions Research and Evaluation Network, University of California, San Francisco

Eric Larson, M.D., M.P.H.—*Optimizing Value Breakout Group* Senior Investigator, Kaiser Permanente Washington Health Research Institute

Risa Lavizzo-Mourey, M.D., M.B.A.—*Infrastructure Breakout Group* Professor Emerita, Robert Wood Johnson Foundation Population Health and Health Equity, Perelman School of Medicine, University of Pennsylvania

Julia Adler-Milstein, Ph.D.—Technologies Breakout Group

Professor of Medicine and Director of the Center for Clinical Informatics and Improvement Research, University of California, San Francisco

Invited Participants

Kathleen Blake, M.D. Vice President of Healthcare Quality American Medical Association

Jennifer Bright, M.P.A. President Momentum Health Strategies Wayne Burton, M.D. Strategic Advisor and Consultant

Ivory Clarke, M.S. Culture of Health Program Director National Academy of Medicine

Matt Eyles, M.P.P. President and Chief Medical Officer America's Health Insurance Plans

Lee Fleisher, M.D., FACC Director and Chief Medical Officer Centers for Medicare & Medicaid Services

Eric Gascho Vice President of Policy and Government Affairs National Health Council

Patrick Gee, Ph.D., JLC Chief Executive Hope Dealer & Founder iAdvocate, Inc.

Brian Gifford, Ph.D. Director, Research and Analytics Integrated Benefits Institute

Christine Goertz, DC, Ph.D. Professor and the Director of System Development and Coordination for Spine Health Duke University

J. Nadine Gracia, M.D., M.S.C.E. Executive Vice President and Chief Operating Officer Trust for America's Health

Amber A. Hewitt, Ph.D. Director of Health Equity Families USA

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Erin Holve, Ph.D. Director of Health Care Reform & Innovation Administration DC Department of Health Care Finance

Libby Hoy Founder and Chief Executive Officer PFCC Partners

Esther Krofah, M.P.P. Executive Director FasterCures

Mohannad Kusti, M.D. Regional Medical Director Pivot Onsite Innovations

Sharon Levine, M.D. Associate Executive Director Permanente Group of Southern California

Tracy A. Lieu, M.D., M.P.H. Director of the Division of Research Kaiser Permanente Northern California

Kristen Lunde, M.P.H. Health Policy Advisor of the Finance Committee U.S. Senate Committee Finance

R. Shawn Martin Executive Vice President and Chief Executive Officer American Academy of Family Physicians

Karen Moseley President and Chief Executive Officer Health Enhancement Research Organization
Frank Opelka, M.D., FACS Associate Medical Director American College of Surgeons

Eva Powell, M.S.W. Associate Director, Clinical Innovation Alliance of Community Health Plans

Gary Puckrein, Ph.D. President and Chief Executive Officer National Minority Quality Forum

Lee Taylor-Penn, M.P.H., M.P.A. Senior Policy Analyst Families USA

Michael Thompson, M.D. President and Chief Executive Officer National Alliance of Healthcare Purchaser Coalitions

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Appendix H

PARTICIPANTS FOR APRIL 27, 2021 MEETING

PCORI PRIORITIES ON THE HEALTH HORIZON APRIL 27, 2021

Panelists and Chair

Neil Powe, M.D., M.P.H., M.B.A. (*Chair*) Chief of Medicine Zuckerberg San Francisco General Hospital

Atul Butte, M.D., Ph.D. Priscilla Chan and Mark Zuckerberg Distinguished Professor University of California, San Francisco

Sachin Jain, M.D., M.B.A. President and Chief Executive Officer SCAN Group and Health Plan

Consuelo Wilkins, M.D., MSCI Vice President of Health Equity and Professor of Medicine Vanderbilt University School of Medicine

Initial Reactors

Dora Hughes, M.D., M.P.H. Associate Research Professor, Health Policy and Management The George Washington University Milken School of Public Health 168 | Priorities on the Health Horizon

Frank Opelka, M.D., FACS Associate Medical Director American College of Surgeons

Anand Parekh, M.D., M.P.H. Chief Medical Advisor Bipartisan Policy Center

Invited Participants

Cybele Bjorklund, M.H.S. Vice President for Federal Strategy, Johns Hopkins University and Johns Hopkins Medicine

Kathleen Blake, M.D. Vice President of Healthcare Quality, American Medical Association

Gwen Darien Executive Vice President for Patient Advocacy and Engagement, National Patient Advocate Foundation

Akin Demehin, M.P.H. Director of Policy, American Hospital Association

Meg Gaines, M.D., J.D., LL.M., Founder and Emeritus Director, Center for Patient Partnerships, University of Wisconsin Law School

Rebekah Gee, M.D. Clinical Associate Professor, Louisiana State University Schools of Public Health and Medicine

Christine Goertz, DC, Ph.D. Professor and the Director of System Development and Coordination for Spine Health, Duke University

Charles (Chip) Hahn, M.P.H. President and Chief Executive Officer, Federation of American Hospitals

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Beverley H. Johnson, FAAN President and Chief Executive Officer, Institute for Patient- and Family-Centered Care

Jenelle Krishnamoorthy, Ph.D. Associate Vice President, Global Policy, Communications and Population Health, Merck

Larry Levitt, M.P.P. Executive Vice President for Health Policy, Kaiser Family Foundation

Enrique Martinez-Vidal, M.P.P. Vice President, Quality and Operations, Association for Community Affiliated Plans

Rachel Nuzum, M.P.H. Vice President, Federal and State Health Policy, The Commonwealth Fund

Jeffrey Schiff, M.D., M.B.A. Senior Scholar, AcademyHealth

Ilyse Schuman, J.D. Senior Vice President, Health Policy, American Benefits Council

Katy Spangler Principal, Spangler Strategies

Emily Stewart Executive Director, Community Catalyst

Vicki Wachino, M.P.P. Chief Executive Officer, Community Oriented Correctional Health Services

PCORI Participants

Nakela Cook, M.D., M.P.H.

Executive Director, Patient-Centered Outcomes Research Institute

Steven Clauser, Ph.D. Katherine Jackstadt, M.S. Jean Slutsky, P.A., M.S.P.H. Laura Lyman Rodriguez, Ph.D.

NAM Leadership and Participants

Michael McGinnis, M.D., M.A., M.P.P.

Leonard D. Schaeffer Executive Officer and Senior Scholar

Ayodola Anise, M.H.S. Ariana Bailey, B.S. Mike Cocchiola, M.P.A. Sarah Greene, M.P.H.