MEETING FOCUS: *Explore opportunities to engage patients and families in care settings during the pandemic, and identifying solutions to the continued and existing gaps on engagement that are especially critical to address at this time. Comprehensively examine and expand actions steps needed to advance and spread system- and policy-level health equity approaches.*

Patient & Family Engagement During COVID-19

- Knitasha Washington of ATW Health Solutions pointed out that the data on disparities and conclusions revealed by COVID-19 are not new, and have constituted a perpetuated emergency for decades. The voices who have shaped the agenda of patient and family engagement have not necessarily represented the diversity seen in the American people, and health systems need to critically examine patient engagement strategies and apply an equity lens to ensure they are representing all people. Structural inequity is one main reason diverse voices and representation have not shaped patient engagement strategies. It is the reason that the incremental progress seen so far is insufficient. The question now, in response to COVID-19, is "what will health care systems do differently?" It is critical to tailor patient engagement strategies to intentionally include underrepresented or underserved populations, instead of applying a vanilla, "one size fits all" policies. Organizations must eliminate tokenism and intentionally incorporate diversity, based on data, early in the process of establishing decision-making groups and in building programs. This requires organizations to apply an equity lens to their internal and external processes, challenge long-standing systems, and demonstrate long-term commitment.
- Beverley Johnson, of the Institute for Patient and Family Centered Care (IPFCC), shared an [FAQs document,](#) recently released, and a [survey](#) IPFCC is facilitating across many different health systems to identify how they are engaging with families during the pandemic. She shared examples of health systems that are doing an exemplary job, such as Children's National, which has revamped their parent navigator program to assist parents with technology questions and demonstrate the utility of telehealth, as well as engage regularly with a diverse group of parents and visitors. Other institutions are transforming ambulatory care and taking advantage of technology to build supportive respectful inclusive telehealth programs, working with patient partners to design the program and understand potential barriers from the beginning. Chicago Health Disparities Center worked with patient partners experiencing serious mental illness and provided options for how to participate in the program. This program, and others like it, are showing leadership in addressing issues of health equity and commitment to building effective meaningful partnerships with patients and families. She addressed workforce issues and noted that leadership is needed to support and build a knowledgeable committed workforce.

Reactors:

- Kathleen Blake, AMA, stated that her organization and many parts of America need to acknowledge their past and not be paralyzed by it, but ask, "What will we commit to doing to intentionally center patient voices?"
- Stephen Hoy, PFCCpartners, has seen a real use for data and information and data transparency, while recognizing that data maybe limited now that people are less inclined to share. Pandemic response plans were developed before our new understanding about the importance of patient and family centered care, and progress made in that domain may be moving backwards during the pandemic. Now we must tackle not just the virus but how we use and mobilize patient family engagement to improve those plans for the future.
- Stacy Palmer, Beryl Institute, indicated that her community at the Beryl Institute realized that during that the current coronavirus crisis health care organizations have moved swiftly. They have been able to see policies updated overnight and implement telehealth in a matter of days or weeks. The current challenge is how to keep that momentum going, and address the important things with that type of speed, while listening to the communities most affected.
- Tamara Cadet, Simmons University, encouraged everyone to understand the diversity that exists even within racial/ethnic communities; they are not monolithic. She encouraged professionals to talk with the communities they serve about what engagement strategy they should be using to reach them most effectively. Finally, she emphasized the importance of plain language and considering health literacy, as the most recent research says that much of the US population has adequate health literacy levels, but not all are proficient. It is important to be conscious of that when starting to develop engagement strategies to truly get people on board.
- Laura Buckley, Camden Coalition, appreciated Dr. Washington's comments around structural inequities in our healthcare system, particularly with leadership who often do not reflect the communities they serve. She said that in thinking about equity we often look at racial disparities, understandably, to highlight those structural issues that are facing the country, and she emphasized Dr. Washington's comment that racism, not race, is in fact a public health

issue. Finally, she noted the acute and ongoing trauma that is affecting both the workforce and the patients that they serve, and she called attention to the need to reduce stigma around seeking support for mental health concerns.

System & Policy-level Strategies to Address Health & Health Care Equity

- Consuelo Wilkins, Vanderbilt University Medical Center, explained that the goal of Vanderbilt's Office of Health Equity—which is separate from the Office of Diversity and Inclusion—is to build on years of work in research and community engagement and expand the institution's focus on education, to foster and catalyze work on health equity. They ensured institutional and leadership buy in by having metrics that are tied to incentives at the leadership level. In response to COVID-19, the command center aimed to integrate health equity into all of the work. They assembled a team of physicians, nurses, social workers, and staff in the Medical Center's business, operations and research sectors to come together to help decide what was most important to do to prevent and address health inequities related to COVID-19. This group focused on: effective risk communication, equitable testing and surveillance, equitable healthcare, broad implementation of telehealth, and equity in COVID-19 clinical research. They relied on data, looking at information on the 46,000 people tested at their institution, examining not only race/ethnicity, but also languages spoken at home and home zip codes of those tested, and stratified that data to identify areas with high community spread. They used that information to identify different languages to translate patient education materials into and to connect with community health centers and community-based organizations in areas with high need. Vanderbilt's intentional effort to ensure equity is aligned with a newly launched institution-wide plan to confront racial inequities, which will include creation of a task force to gather data and development of a set of recommendations for the CEO and board, anti-racism training for all C-suite leaders and the board, as well as additional resources to make sure that anti-racism is built into medical education and the curriculum.

- Tekisha Everette, of Health Equity Solutions, shared that her organization is focused on the social determinants of health, enabling health systems to understand and leverage their power and position to impact what is happening outside of the system in order to allow people to live their healthiest lives. She noted that the current health care system is built on inequity, with better care provided for certain populations over others. To change the health care system, she recommended understanding the historical disadvantages and the power imbalance caused by structural racism and five key steps states or health care institutions can take to ensure health equity:

  1) Institutionalize inclusion. There must be an institutionalized way of including individuals who do not reflect the majority positions, backgrounds, and culture into the organization. There needs to be a group of people who focus on embedding an equity lens, asking critical questions—no matter what the goal, policy or project is trying to achieve— on how that activity impacts and or influences health equity or inequity in general, particularly racial equity.

  2) Confront racism and embed accountability. This radical solution requires institutions to move beyond talking about racial disparities and race, to talking about the fundamental root cause of institutional, interpersonal, and internalized racism. It requires acknowledging that no one on this call has ever seen a state of equity.

  3) Collect granular race/ethnicity data. This data can be used as an indicator of progress towards health equity and dismantling racism. Several states are stratifying their COVID-19 testing rates by race/ethnicity, but they should also stratify testing data by gender, location, and zip code to help localities improve their testing strategies.

  4) Foster access to medical care & clinical trials. Engaging and building trust in marginalized communities as it related to medical care and research is necessary so that health care providers are better able to understand and offer targeted treatments that will be most effective for them.

  5) Support bridges to medical care. Increased access to medical services and health insurance for populations of color is critical, especially during COVID-19.

  She emphasized the importance of creating specific, achievable, and measurable health equity goals in order to know if we are dismantling racism.

- Cara James from Grantmakers in Health noted that the disparities described in previous presentations are not unique to the current pandemic. She encouraged the Leadership Consortium, as it thinks about fostering collaboration, to make health equity a long-term priority. She encouraged institutions to examine their funding for health equity compared to other priority areas, realizing it is often a small group of people or a single individual in an organization with limited resources trying to address health disparities and equity. She emphasized the role of leadership who are committed to equity and who offer continued, cross-sectoral, and sustained focus on these topics. She encouraged institutions and leaders to ensure they are approaching and engaging with communities with humble inquiry— defined as drawing someone out by asking questions to which you do not already know the answer—to make sure that they are working with communities to identify the areas that should be focused on, (rather than taking a top down approach), opportunities to improve health, and areas where the working relationship can be improved to foster

collaboration. Given the new focus on engaging with experts in equity and diversity, it is important to be aware of demands on experts' time and to compensate them adequately. She emphasized the importance of data collection to measure or monitor progress and identify disparities. Looking at large national reports, from AHRQ's National Healthcare Quality and Disparities Report or data from the CDC, much is unknown. It is important to examine how the health system prioritizes data collection so that it is possible to do an apples to apples comparison, because even within the states there are a myriad of ways in which data on race and ethnicity are being captured. It is not possible to include factors such as language or the social determinants of health on a dashboard, if it is not being collected. The disparities and inequities that we see in our system have taken years to build and cannot be cured in a few months. It is important to tackle the structural and systemic issues of racism. She concluded with noting the importance of developing programs to train individuals early to ensure there is a robust pool of applicants for health care positions, as well as other fields such as the law, education, community advocacy, and health policy.

Reactors:

- Christopher Koller, Milbank Foundation, suggested focusing on state health policy, which creates the ecosystem in which these initiatives operate, and emphasized the importance of a systemic approach to addressing inequities. He also called for consistently measuring performance based on race and ethnicity, and gave the example of the inability of Medicaid agencies across the country to systematically collect and report on these data. He drew a line from data collection to quality improvement, noting that we improve what we measure, and suggesting Medicare as a good starting point because the data is in one place.
- Monica Bharel, MA Department of Public Health, described her department's implementation of a health equity plan, using a precision public health view to examine existing data and highlight the social determinants of health. They also used their limited resources to target those areas where people need programs and policies the most. The Department of Health eventually scaled up to focus specifically on racial health equity, looking at individual, institutional, and structural racism both internally and externally, training senior leaders, and examining their work through a health equity lens (e.g., how they award grants, conduct diversity training, and hire staff).
- Melissa Simon, Northwestern University Fienberg School of Medicine, agreed that equity needs to be woven into everything, including the structural barriers and opportunities at every single level, such as leadership, to work towards racial justice and being actively anti-racist, not just eliminating racism. To achieve this, she echoed the suggestion of humble inquiry, emphasizing genuine communication with deep listening and learning, and being vulnerable and sitting in discomfort, which can be uncomfortable for those in positions of privilege.
- Regina Davis Moss, APHA, highlighted the distinction between health equity and diversity and inclusion. She shared that sometimes diversity and inclusion programs assume that employees have to change to fit into a workplace culture, which is not reflective of embracing identity or sustainable. She echoed that a focus on health equity should be aimed at the distribution of resources, disadvantages experienced by certain groups, and naming racism explicitly.

Question and Answer

- Lynn Walton Haines: "Initially when I bring up equity and workplace, I'm often told it's a priority, but we don't have indicators to measure. How do we move our organization beyond just reporting disparity by race, but to action, to include patients and communities and measure effectiveness that organizations will acknowledge?"
  - o Bev Johnson suggested that a beginning point is to select a group of leaders in the organization and patient, family and community partners and listen to this webinar, to help understand both the issues and key strategies. The next step is to support senior leaders in having honest conversations, for example, in a town halls with experienced facilitators, so they have an opportunity to hear directly from the communities they serve, as well as their staff. Directly addressing racism requires the development of action plans and holding systems accountable.
  - o Tekisha Everette indicated that measuring health care data is significant, but ultimately, what matters is what is done with the data. It becomes a conversation about how to engage individuals, both within the organization as well as the people who are being served, and understanding why gaps exists. It requires asking, "why?" to get to the root cause of the disparity and then be able to create action to change it.
- Susan Devore, Premier Inc. (Co-Chair of the Value Incentives and Systems Action Collaborative): "I lead a healthcare supply chain and technology company, and I'm wondering whether I have health equity or disparities in our employee population, which spans the country. We all have the same employee benefit plans and access to those benefits. But I'm wondering whether we still have health disparities, and how we would most effectively measure that?"
  - o Knitasha Washington suggested examining compensation across your organization and across similar roles by race/ethnicity and gender and see where those disparities exists. Most organizations that go through the exercise

      find that disparities exist. Consider employee satisfaction and strategy these data by race/ethnicity and gender to understanding what employees may be experiencing.

- How can we take advantage of this window of opportunity to make durable structural and systemic transformations that last in the long term? How can we develop and sustain partnerships as allies, for example, with historically black colleges and universities and not exhaust black, indigenous, or other people of color whose time may be limited, and avoid burnout or tokenism?
  - Cara James indicated that self-care is important. Find your support groups and make sure that you are taking care of yourself, because we have a long road ahead of us. It is crucial to develop a roadmap for an equitable recovery during the pandemic and think strategically about building data collection, analysis and reporting into our system to ensure we can address questions in the future, such as who should receive the vaccine.

Thank you to collaborative co-chairs, speakers, and invited reactors:

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