Center for
Healthcare
Innovation

2019 Diversity, Inclusion, & Health Equity Symposium Executive Summary

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Introduction

On June 26, 2019, the Center for Healthcare Innovation (CHI) held its 9th annual Diversity, Inclusion, & Health Equity Symposium in Chicago, IL.

This annual symposium was a collaborative event that focused on health equity and health disparities in the United States. The event brought together leading healthcare professionals, executives, physicians, patient groups, patients, researchers, academics, clinical trial professionals, and diversity and inclusion advocates to discuss health equity in the life sciences and health sectors. The workshop featured a Distinguished Keynote Address by Dr. Jonathan Holloway, Provost of Northwestern University. Panel discussions included understanding how social determinants impact health inequities, how diversity driving business outcomes, achieving diversity in clinical trials, and the need for culturally competent healthcare professionals.

This executive summary aims to:

- Define the challenges for patients, providers, and other professionals in addressing health equity and health disparities
- Summarize the innovative ideas and potential solutions on innovation and access
- Discuss best practices to better serve patients both currently and in the future

The paradigm shift towards patient-centered care and increasing emphasis on equitable access to care and the need for diversity at all levels highlights the opportunity to make substantial improvements in the near future. This executive summary aims to serve as a guide to ideas and insights regarding the challenges and calls to action in addressing these issues.

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Background

The 9th annual Diversity, Inclusion, & Health Equity Symposium was a leading annual, collaborative event that focused on health equity and health disparities in the U.S. The symposium brought together leading healthcare professionals, executives, physicians, patient groups, patients, researchers, academics, clinical trial professionals, and diversity and inclusion advocates to discuss health equity in the life sciences and the health sectors. The symposium focused on the latest trends, challenges, opportunities in both the marketplace and workplace, with a specific focus on how to best serve an increasingly diverse patient base. We also aimed to address the broader health disparity challenges in the U.S., and the symposium equipped attendees with the latest insights and ideas. Attendees learned practical solutions, share perspectives, and meet new industry and marketplace colleagues.

Panel: Understanding How Social Determinants Impact Health Inequities

MODERATOR: Dr. Marty Martin, PsyD, MPH, leads a portfolio of degree programs from the Health Sector Management MBA to the MBA/MPH at DePaul University. Throughout his career beginning as a clinical health psychologist and including his past roles as Director of Diversity at The Johns Hopkins Hospital, Marty has launched innovative programs in higher education and healthcare by identifying, leveraging and nurturing diversity. His track record as an innovator and entrepreneur has resulted in Marty speaking around the world and locally on the link between diversity and creativity, innovation and design thinking. As an academic, he has authored two books, numerous book chapters, and over 100 refereed articles. His work has been featured in the Wall Street Journal, USA Today and Chicago Tribune.

Dr. Kimberly E. Davis, PhD, MS, is a Senior Research Scientist and Director of the Community Outreach Core in CCRTD at Clark Atlanta University. Dr. Davis is an accomplished scientific research professional with expertise in health services research, outcomes research, and observational studies. Dr. Davis received her B.S. and M.S. degrees from Alabama A&M University and Ph.D. degree from Florida State University. Her research emphasis includes research in cancer health disparities and falls into four broad categories: cancer etiology, nutritional epidemiology, minority participation in research studies, and cancer survivorship. She conducts research to study relationships between various dietary factors and prostate cancer risk, with an emphasis on racial and ethnic disparities.

Dr. Denise Hines, DHA, PMP, FHIMSS, is Chief Americas Officer at HIMSS. Dr. Hines is an award-winning, nationally recognized expert in healthcare technology. Dr. Hines has more than two decades of healthcare experience in a variety of settings, including health systems, physician offices, home health, technology vendors, consulting, state government and revenue management. Dr. Hines recently was a member of the HIMSS Board of Directors and the Chair Emeritus for HIMSS North America Board of Directors. She is the past president of the HIMSS Georgia Chapter and was recognized as the 2012 HIMSS Chapter Leader of the Year. In 2017, she was recognized with the prestigious Women of the Year in Technology – Small Enterprise Award from Georgia's Women in Technology (WIT).

Ms. Mindi Knebel, MBA, is the founder & CEO of Kaizen Health. A startup junkie who is passionate about social entrepreneurship, Mindi has worked across several industries and has seen companies from inception through successful exit. Mindi was on the founding team at MATTER, a healthcare technology incubator formed through a public-private partnership in the city of Chicago. Mindi has led sales operations, accounting/finance, human resources and corporate development initiatives for growth stage companies in service, veterinary, and technology industries. Mindi holds a bachelor's degree from the University of Iowa and a master's in business from Colorado Technical University. She enjoys spending time with family and friends, running, yoga, reading and is an avid Packers, Iowa Hawkeyes, Cubs, Bulls and Blackhawks fan.

Mr. Paul Ceverha is a managing director with AArete's healthcare strategy team. He has an extensive track record of developing new and innovative approaches to complex clinical, IT, operational, and market opportunities. Paul has served in various roles as a senior executive, program manager, CTO, industry subject matter specialist, and technical architect. He has extensive experience in, and broad knowledge of, clinical and business intelligence, and regularly advises hospital systems on the enablers required for bearing risk and improving outcomes on populations.

Dr. LaMar Hasbrouck, MD, MPH, A nationally recognized health leader, Dr. LaMar Hasbrouck is a Senior Consultant for Initium Health, a public benefit corporation, which has formally committed to a public benefit through the improvement of human health. He previously served as a Senior Advisor to the American Medical Association developing strategies to eliminate gaps in chronic disease prevention. Dr. Hasbrouck has served on the faculty at Emory University School of Medicine, Morehouse School of Medicine, New York Medical College, and the University of Illinois at Chicago's School of Public Health. He received his BA and MPH degrees from the University of California-Berkeley, and graduated Dean's Scholar from the David Geffen School of Medicine at UCLA.

Ms. J. Mori Johnson, MA, is the Ambassador and Health Equity Engagement Director at the American Medical Association (AMA), where she has been employed for the last 23 years. She has held numerous communications, health policy and director positions during her tenure. Currently, Mori serves on the Executive Committee of the AMA's Diversity and Inclusion Work Group. She graduated from the Rutgers University Honors Program, with a Bachelor's degree in Communications and Linguistics and then moved to Chicago to pursue a career in health policy. In 2003, she earned a MA in Multicultural and Corporate Communications from DePaul University. Mori enjoys traveling, the art of story-telling and is a self-identified foodie. She resides in the South Loop with her husband Robb Gipson and their rescue cattle dog, Rufus.

Dr. Suzet M. McKinney, DrPH, MPH, currently serves as CEO and Executive Director of the Illinois Medical District (IMD). The IMD is a 24/7/365 environment that includes 560 acres of medical research facilities, labs, a biotech business incubator, universities, 4 hospitals, raw land development areas and more than 40 healthcare related facilities. Dr. McKinney is the former Deputy Commissioner of the Bureau of Public Health Preparedness and Emergency Response at the Chicago Department of Public Health, in addition to overseeing the Department's Division of Women and Children's Health. Dr. McKinney holds her doctorate degree from the University of Illinois at Chicago School of Public Health, with a focus on preparedness planning, leadership and workforce development.

Social determinants, defined as the conditions in which people are born, grow, work and age, are shaped by the distribution of money, power, and resources at all levels.[1] These determinants have an impact on individual and community health. As brought up by a panelist, "the term social determinants of health is 102 years old and we are now just addressing it," highlighting the lack of focus that this topic and its impact has received in the past. To further this, despite the increase in conversation about the importance of social determinants, it is another effort to take concrete steps in addressing these disparities. One panelist mentioned his organization as one that is providing concrete actions such as making opportunities for vulnerable communities to have access to education, employment, and better infrastructure. It was stressed by the panelists that when addressing disparities that arise from social determinants, the best approach is to think local and act global.

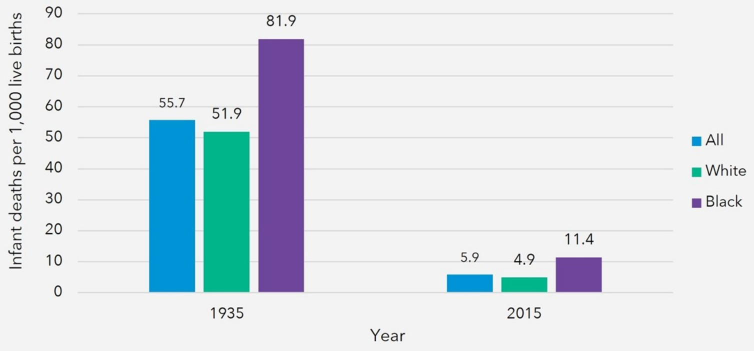
The relationship between social determinants and health inequity reasserts the fact that in order to address one, the other must be addressed as well. More specifically, in order to reduce health inequities in a community, action must be taken to reduce socioeconomic inequalities. Conversely, increases in inequity regarding wealth and income can increase this issue in the healthcare sector.[2] When examining community risks for particular diseases, it is often the case that these discussions fall into "lifestyle drift", which is the tendency in public health discussions to focus on individual behaviors (such as diet, smoking, and drug use) rather than the underlying causes that can lead to these behaviors.[2]

"The relationship between social determinants and health inequity reasserts the fact that in order to address one, the other must be addressed as well."

One of the panelists provided Columbus, OH as an example social determinants effects and how those factors play into individual behaviors. Columbus has the highest rate of infant mortality in the United States. Research has attributed the high rate to a combination of lack of transportation to medical services and minimal access to fresh food for those requiring monetary assistance. Despite SNAP and WIC being frequently accepted, only about 15% of those accepting locations had fresh food options. A low-quality diet is an individual action but, it is the combination of the social determinants that lead to a situation where babies are malnourished and lack transportation to medical care to treat that condition.

Exhibit 1

Infant Mortality Rate by Race, United States, 1935 and 2015



SOURCE: Singh, Gopal K., et al. "Social Determinants of Health in the United States: Addressing Major Health Inequality Trends for the Nation, 1935-2016." International Journal of MCH and AIDS (IJMA), vol. 6, no. 2, 1 Oct. 2017, pp. 139–164., doi:10.21106/ijma.236.

Social determinants also play a role in community health expectancy. Expectancy rates have vary significantly among demographics. For example, in 2015, African American/Black infants had a mortality rate 2.3 times higher than that for White infants.[3] Regarding individual behaviors and health expectancy, a panelist stated that "people do and change behaviors with their expectations," meaning that certain communities have disease expectations, and people often act in a way that resembles the expectation, even when social determinants do not have as strong of an influence. They posed the question of how can we get certain populations to move away from previous disease expectations and help educate. The importance of answering this question was highlighted by a panelist using the example of prostate cancer, which they described as 99% treatable if found early. In disadvantaged communities, personal health and preventative screenings are not a top priority for many when compared to the financial cost, causing the condition to be found later than it otherwise could have been. Key ideas shared to address this discrepancy were increasing both access to care as well as community engagement to emphasize the importance of screening.

Another solution proposed was the implementation of technology and advancing organized medicine. These can lead to practice transformation, especially in smaller clinics, and policy creation should be leveraged to help drive this change. One of the greater advantages of this approach is it allows for people to show total community health and use of particular services or programs with patients electronic health records (EHRs) and other health information technology (HIT).[4] This use has also been on the rise, with HIT utilization growing 133% between 2009 and 2013.[4] The benefit of this is movement of measurements from volume to value, leading to better assessments overall. As well, this allows hospitals to better know the history and environment of a patient, leading to more individualized care and helping to lower readmission rates as patient conditions outside of the hospital can be addressed.

The topic of reaching and activating communities was also addressed by this panel and those in attendance. One individual emphasized that while groups may offer services within the community, often those communities are unaware of the services due to the lack of advertisement for the services themselves. Miscommunication both internally and between the groups and the patients, acts as a barrier for individuals to access assistance. There is a need to find the resources that can connect the actions of groups and partnerships between large and smaller institutions to best reach those in need. Additionally, there can be a disconnect between the services groups want to offer and the needs or wants of the community they are offering in. A proposed solution to this issue was to emphasize community-driven solutions (an activated community) to ensure that their priorities match the services they are being offered. Precision medicine was also provided as a potential solution, working to prevent rather than having to treat the outcomes. Another panelist noted that gaining predictive data relies on how and who is asking the questions within a community. The final highlight was the need for the creation of communities between providers and groups that address these issues and offer different solutions to barriers, gaining community input that allows for “targeted interventions.”

”Miscommunication both internally and between the groups and the patients, acts as a barrier for individuals to access assistance.”

Panel: How Diversity Drives Business Outcomes

MODERATOR: Dr. Cheryl Beal Anderson, PharmD, MBA, is the Vice President & Head of Regulatory Affairs and Quality at Upsher-Smith Laboratories. Her prior role was Senior Director, Global Regulatory Affairs at Lundbeck, a global CNS pharmaceutical company committed to making progress in mind and developing innovative treatment for Psychiatric and Neurologic diseases. The corporate headquarters are located in Valby, Denmark and US Offices in Deerfield, IL. Anderson leverages 20 + year career experience and knowledge in NDA/BLA, ANDA, FDA negotiations, FDA Advisory Committee experience to support the company's vision to expand capabilities needed to obtain new drug approvals in the United States with an inclusive and collaborative leadership style with teams based in Valby, Denmark.

Ms. Cherie Coleman, MSC, is currently Program Manager within the Payment Innovation Division at Anthem, Inc. She's focused on operations management for their Enhanced Personal Health Care Program models which delivers excellence for the five dimensions of a high performance health system: quality, access, efficiency, equity and healthy lives. Cherie has held a leadership role in various capacities within the Health Care industry beginning her career at the University of Chicago Hospitals. In 2012, she joined the IL Diversity Council as the Activities and Events Chair. In 2016, Cherie became a Certified Diversity Professional (CDP) and stepped into the role of Advisory Board President. She received a Masters in Communications degree with an emphasis in Business Leadership and Change Management from Northwestern University.

Ms. Lydia Rohn is a strategic HR leader with over 25 years experience for organizations in healthcare as well as manufacturing, public education, technology and retail. Lydia recently lead HR at Pinnacle Dermatology LLC and QuadMed. Prior to QuadMed, she led HR teams for the healthcare and pharmacy divisions at Walgreens. Passionate about advancing women leadership and aligning talent to organizational strategies, she has been a board member of HBA (Healthcare Businesswomen's Association) in Chicago since 2010 serving as President, Vice President, Mentoring Director, and currently serves as a board advisor. She also advises the leadership board for Evanta Chicago and serves on the Education committee of the Private Directors Association.

Ms. Gloria Woods serves as a Senior Consultant and Facilitator with the Kaleidoscope Group. Gloria has over 20 years of experience as a consultant, trainer and diversity practitioner. She specializes in diversity strategy implementation, training design and delivery, and measuring results. These solutions are tailored to support an organization's mission and goals. Her extensive experience spans many industries and organizations. She has designed and delivered consulting solutions, and conducted a full portfolio of diversity and inclusion education for clients such as: The Federal Reserve Bank of Atlanta, Blue Cross/Blue Shield, Nationwide Insurance, Office Max, Kraft Foods, Spencer Stuart, Aids Foundation of Chicago, and the YWCA Evanston/North Shore.

Mr. Sergio Alcocer is the founder of Rest of the World. In 1999, Sergio co-founded LatinWorks in Austin, Texas. The innovative shop opened without any clients and was driven by a mission to transform the image of the Hispanic agency by erasing stereotypes and delivering world-class strategy and creative to Fortune 100 clients. LatinWorks was named Multicultural Agency of the Year multiple times by both Advertising Age and ADWEEK and, in 2014 and 2011, was named one of the top 10 agencies in America by AdAge. Sergio earned an EMBA at the Berlin School of Creative Leadership and he is now a PhD candidate at the University of Texas at Austin.

Ms. Dima Elissa, MBA, was selected by Chicago magazine as one of the Top Women in Tech, Chicago Innov's 50 on Fire and by Chicago Tribune's BlueSky Vault as one of the Top 100 Entrepreneurs in Chicago. Her current ventures, VisMed-3D, a 3D biomedical design and consulting firm, is in keeping with her thirst for new technology and innovation and Symptomatic.io, a blockchain healthcare platform enabling interoperable big data to flow. Alongside these novel start-ups, she is pursuing her passion – devoting time, energy, and guidance to women founders and entrepreneurs. As an adjunct faculty member or Entrepreneur-in-residence, teaching Entrepreneurship or as an in-demand speaker, she exemplifies her commitment to giving back and paying it forward.

Ms. Terri Sanders, MPH, is an award-winning marketing, communications and brand strategist with more than 17 years of experience. She currently serves as the Vice President of Enterprise Marketing and Communications for HIMSS, a global, cause-based, not-for-profit focused on transforming health through information and technology. In this role, Terri is responsible for global management of HIMSS and HIMSS-related brands as well as enterprise communications, marketing and public relations. She is the first African-American and African-American woman to serve as a member of its Executive Leadership Team. Terri holds a Bachelor of Science from the University of Michigan. She also holds a Master of Health Management and Policy from the University of Michigan's School of Public Health.

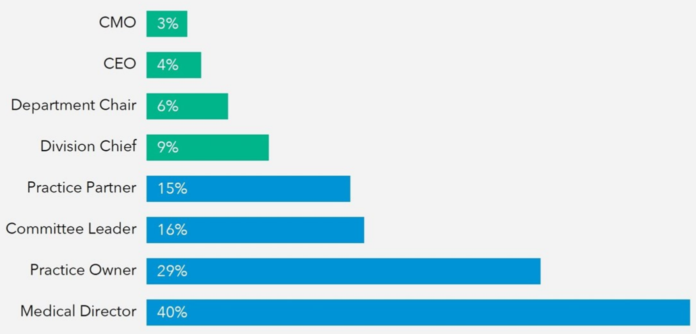
The How Diversity Drives Business Outcomes panel focused on the issues surrounding diversity in the business sphere, proposed solutions to these challenges, and the benefits of having a diverse community and perspectives. Although the importance of diversity has become a more prominent topic in recent years, substantial improvements still need to be made, despite it being shown that diversity helps improve a company's performance. In a study that included 346 companies from the United States and United Kingdom, it was shown that those in the top quartile for diversity were more likely to have industry leading profitability. Yet, between 2015 and 2017, companies increased gender and ethnic diversity by only 2% and 1%, respectively.[5]

When beginning to address these issues, panelists communicated the distinctions that diversity is not inclusion and inclusion is not equity. Without inclusion, you cannot have true diversity. Trust needs to be fostered within a culture to be able to obtain all three.

Panelists also emphasized that this issue is not one of people asking for opportunities, but rather one of groups not receiving the opportunities they ask for. Regarding women, only 4% of healthcare CEOs, 6% of department chairs, 9% of division chiefs, and 3% of chief medical officers are female, despite there being no significant gap in education levels between men and women.[6] There are also cultural nuances that create division and differentiation that lead to these discrepancies. These nuances are among the main points of focus for creating a more diverse community in businesses.

Exhibit 2

Women Physicians in Leadership



SOURCE: American Medical Association. "Women in Medicine by the Numbers."

One of the major factors is obtaining commitment from an organization and getting buy-in from leadership. As one panelist asserted, an organization will buy-in when they see what it brings to their life or in other words, “the enhancement of their world.” Yet, to see these enhancements, the tone must be set by leadership. To accomplish that another panelist argued that we need to keep driving change with business outcomes, showing that they are not only improving their company’s culture but also their profits.

Another point of issue is addressing implicit bias and enabling growth within a company. There are more than 150 cognitive biases with 5 that have direct impact on the workplace: affinity bias, halo effect , perception bias, confirmation bias, and group think.[7] As of last year, 20% of large U.S. companies provided implicit bias training with 50% offering it in the next five years.[7] The question then arises of how to make these trainings as meaningful as possible, rather than just a protocol. One panelist suggested that it is important to ensure that the trainings are not simply “covering” in this, as it is crucial to be authentic in these settings to foster true improvement. When addressing inadequate trainings and protocols, panelists maintained that the problem is not the strategy but who the strategy is being made with; without a diverse group of opinions in creating protocols and measurements, it is not feasible to create a holistic and effective means of addressing bias and diversity within an organization.

The collaborative efforts required to achieve meaningful change was continuously highlighted by the panel. In particular, panelists encouraged individuals to not only be brave in addressing issues, but also to use their voice to uplift others in the same space. Said another way, “lift as you climb.” In addressing disparity, one panelist described a collaborative effort as “see what I see, then see what I miss.” We are all victims to our own inherent biases, and to address them individuals must aid each other for the organization to grow as a while.

> *”We are all victims to our own inherent biases, and to address them individuals must aid each other for the organization to grow as a while.”*

Distinguished Keynote Address

Jonathan Holloway, PhD

Provost of Northwestern University

Jonathan Holloway became Provost of Northwestern University on August 1, 2017. He is Northwestern University's Chief Academic Officer and an ex officio member of the faculty of each school. In this role he:

- Supervises the educational policies and academic priorities of the University.
- Encourages and coordinates initiatives in undergraduate and graduate education.
- Oversees preparation of the university's annual budget.
- Acts on faculty appointments and promotions.
- Directs allocation of resources and space to academic units.
- Is the acting chief executive officer in the absence of the President.

Provost Holloway specializes on post-emancipation United States history with a focus on social and intellectual history. He is the author of Confronting the Veil: Abram Harris Jr., E. Franklin Frazier, and Ralph Bunche, 1919-1941 (2002) and Jim Crow Wisdom: Memory and Identity in Black America Since 1940 (2013), both published by the University of North Carolina Press. He edited Ralph Bunche's A Brief and Tentative Analysis of Negro Leadership (NYU Press, 2005) and co-edited Black Scholars on the Line: Race, Social Science, and American Thought in the 20th Century (Notre Dame University Press, 2007). He wrote an introduction for the 2015 edition of W.E.B. Du Bois's Souls of Black Folk, published by Yale University Press, is under contract with Oxford University Press for a survey tentatively titled The Cause of Freedom: An Introduction to African American History, and is currently working on a new book, A History of Absence: Race and the Making of the Modern World.

Before moving to Northwestern, Holloway was the Dean of Yale College and Edmund S. Morgan Professor of African American Studies, History, and American Studies at Yale University.

Holloway received a bachelor's degree with honors in American Studies from Stanford University and a PhD in History from Yale University. He began his academic career at the University of California, San Diego, before joining the faculty at Yale in 1999.

The Distinguished Keynote Address was given by Jonathan Holloway, PhD, the Provost of Northwestern University. Provost Holloway focuses on post-emancipation United States History with a focus on social and intellectual history and is the author or Confronting the Veil: Abram Harris Jr., E. Franklin Frazier, and Ralph Bunche, 1919-1941 (2002) and Jim Crow Wisdom: Memory and Identity in Black America Since 1940 (2013), both published by the University of North Carolina Press. Holloway previously was the Dean of Yale College and Edmund S. Morgan Professor of African American Studies, History, and American Studies at Yale University. He also serves on the Chicago Botanic Society, Illinois Humanities, the National Humanities Alliance, the Society for United States Intellectual History, and the Organization of American Historians.

Holloway focused his talk on the importance of leadership and the transition that top schools need to undertake to be truly prepared for first generation and lower-income students in a way that allows them to succeed to their fullest potential. He stressed that it is important for every individual to find their mentors, and that sometimes we need to be willing to seek them out ourselves. Most importantly, it is important to remember that mentors need not look like us, but rather share passions with a mentor genuinely supporting a mentee's ambitions. He also stressed that these mentorships are of an even higher importance as there is a clear lack of diversity in higher education. Lastly, Holloway once again stressed that we all must recognize our own potential as well as the potential of others.

"[I]t is important for every individual to find their mentors, and that sometimes we need to be willing to seek them out ourselves."

Panel: Achieving Diversity in Clinical Trials: Barriers and Proposed Solutions

MODERATOR: Dr. Andres Quintero, MD, MPH, MBA, is the Illinois Field Medical Director for Pfizer's Biopharmaceutical group, within the Internal Medicine division of North America Medical Affairs (cardiovascular and metabolic medicine). He functions as division's Chief Medical Officer for Illinois. He was previously at Navigant as an Associate Director, where he helped provider systems reduce unwarranted variation in clinical care by combining rigorous analyses of data with high quality peer-reviewed medical literature, and by identifying and addressing barriers to adoption for data-informed strategies. He holds an MD from Penn State College of Medicine, and MPH and an MBA from Johns Hopkins University, and a BA in Molecular Biology from Brown University.

Ms. Regina Greer-Smith, MPH, is a member of the Advisory Panel for Patient Engagement at the Patient Centered Outcomes Research Institute (PCORI). Regina is the President and Owner of Healthcare Research Associates, LLC. Regina's work includes building and maintaining collaborations between communities and stakeholders that enable improved healthcare outcomes. Regina is a consultant /healthcare coordinator to agencies providing services to developmentally and intellectually disabled adults in Illinois and the use of mobile technology to enable collaboration between patients/caregivers and providers. She is the developer and principal investigator of The S.T.A.R. Initiative. The mission of The S.T.A.R. Initiative is to increase minority participation in patient-centered outcomes research and clinical trials.

Dr. Marla Mendelson, MD, is the Medical Director of the Northwestern Adult Congenital Heart Center and the Heart Disease in Pregnancy program of the Women's Cardiovascular Health program of the Bluhm Cardiovascular Institute founded the Heart Disease and Pregnancy program and the Adult Congenital Heart program. For women with congenital heart disease, she provides preconception planning, contraceptive counseling, and care of women through pregnancy working closely with the woman's obstetrician. She is an associate professor of medicine and pediatrics at the Feinberg School of Medicine. Dr. Mendelson was recently appointed the co-director of the Women's Health Research Institute at Northwestern promoting sex and gender inclusion in research studies and clinical care to improve Women's health.

Dr. Karriem Watson, DHS, MS, MPH, is a Senior Research Scientist with the University of Illinois Cancer Center and Co-Director of Community Engaged Research for the UI Cancer Center at UIC and Mile Square Health Center. His areas of expertise include advancing research through strengthening and building community-academic partnerships and addressing barriers and facilitators to screening and navigation among underserved populations. Dr. Watson is a Multi PI on an NCI R21 examining the impact of breast cancer screening navigation among African American women and Multi-PI on a NCI U54 Pilot examining the social networks of African American men engaged as Citizen Scientists to advance prostate cancer screening. He also leads a PCORI Eugene Washington Engagement award aimed to engage patients as equitable partners to research and cancer center leadership.

Dr. Neelum T. Aggarwal, MD, is the Chief Diversity Officer at American Medical Women's Association. She is a cognitive neurologist, clinical trialist and researcher in the field of population health and aging. She is the Senior Neurologist for the Rush Alzheimer's Disease Center (RADC) Clinical Core in Chicago; Director of Research at the Rush Heart Center for Women, and an Associate Professor in the Departments of Neurological Sciences and Rush Alzheimer's Disease Center at Rush University Medical Center. She completed her medical degree from the Rosalind Franklin University - Chicago Medical School, completed her neurology residency at Henry Ford Hospital in Detroit, Michigan, and completed an aging and neurodegenerative disorders fellowship at the Rush Alzheimer's Disease Center.

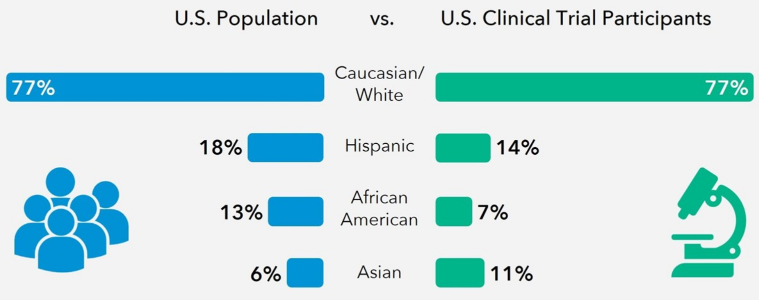
Dr. Helen Kellar-Wood, PhD, has over 15 years' experience in Healthcare and the Pharmaceutical industry, working for several companies and academic institutions in both the UK and the US. Helen has been with Bristol-Myers Squibb for 7 years. With a background in public affairs and corporate communications, Helen now leads Advocacy, Diversity and Patient Engagement strategy for the autoimmune and oncology portfolios at Bristol-Myers Squibb. Helen focuses on health equity issues and facilitates collaborations with a broad variety of patient facing and diversity organizations to identify ways Bristol-Myers Squibb can better understand and incorporate patient, caregiver and advocacy perspectives in order to improve our clinical studies.

Dr. Sumant Ramachandra, MD, PhD, is Chief Science and Technology officer at Baxter International Inc. Dr. Ramachandra joined Baxter in 2017. Previously, he worked with Pfizer, most recently as Senior Vice President, Head of Research & Development, Pfizer Essential Health. He serves as executive sponsor of the Asian Leadership Network, a business resource group focused on creating bridges for cultural diversity, attraction and development of talents and growth opportunities to increase the impact of Baxter business with the Asian community. Dr. Ramachandra obtained his bachelor's degree in biochemistry, a PhD in immuno-oncology labs, experimental pathology and his MD from Rutgers University. He is accredited by the American Board of Internal Medicine and received an MBA from the Wharton School at the University of Pennsylvania.

Encouraging, if not requiring, diversity in clinical trials is an essential factor in equitable healthcare. For industry sponsored clinical trials, the distribution of age, sex, race and high-burden medical comorbidities often does not match disease epidemiology, which limits the study inferences that we can draw on safely and ethically for underrepresented populations. When it comes to defining minority groups accurately and addressing gaps in representation, the FDA only provides "guidelines" rather than mandates to ensure that groups are properly accounted for in a trial. This means that drugs are being approved by the FDA without gender and race being properly accounted for. Between 2015 and 2018, 31 cancer drugs were approved. Of those, 24 utilized clinical trials where less than 5% of the patients were black despite being 13% of the nation's population as of 2018.[8] This topic can have dangerous implications as underrepresentation can lead to unanswered questions about how a disease or treatment can affect a population, leaving minority groups disproportionately vulnerable. Only recently has there been a shift in how we measure and analyze data in trials, and we need more accountability and transparency in the results.

Exhibit 3

Race and Ethnicity of U.S. Population and Participants in Clinical Trials



SOURCE: U.S. Census Bureau. "QuickFacts: UNITED STATES."; U.S. Food and Drug Administration. "2017 Drug Trials Snapshots Summary Report."

Also noted was the issue of little to no patient engagement at the drug development stage. Community engagement in research is defined as "a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership,".[9] As one panelist asserted, communities that are most in need of a particular drug need to be the primary focus of the clinical trial, as well as provided education and other opportunities to raise awareness about their options. Engagement with these communities early in the process is important for three main reasons: to build trust in communities, to aid in the enrollment of a sufficient number of patients in a clinical trial, and to ensure that the findings are translated to and adopted by the intended beneficiary communities.[9]

One of the main issues regarding having a representative patient group highlighted by the panel was the exclusionary criteria that often disengages patients and entire communities. Countless groups are being left out of trials for a variety of factors such as criteria, trust, and failing to get information to where people live. A panelist asserted that with the exclusionary criteria, we are not providing patients with a "real life" cause of exclusion. When this occurs, the patient is not only disengaged from that study but also potential future studies, limiting the potential patient population to include in trials. Regarding trust, it is necessary that those administering a trial ask for permission in order to establish a relationship; within this same idea, a panelist noted that often who is asking matters as well as the experiences that they bring. Another panelist suggested looking at this idea by engaging groups as "citizen-scientists" as often the communities themselves have valuable information that otherwise would have been inaccessible. Above all else, the panelists noted that these efforts take time and that those conducting trials must begin the process of engagement and trust building earlier rather than later.

"Countless groups are being left out of trials for a variety of factors such as criteria, trust, and failing to get information to where people live."

Currently, those conducting trials are increasingly asking for participants to do more, without focusing on the education to make them fully aware of the process they are involved in. Trial literacy has not been a focus, and in some cases the concepts behind the trial are not even introduced in the community. A panelist asserted that "direct marketing" needs to occur not only to show people why their trial is important, but also to ensure that those in a community know about confidentiality, which potentially can help build trust.

Panel: The Need for Culturally Competent Healthcare Professionals

MODERATOR: Ms. Erickajoy Daniels, MS, is the Senior Vice President and Chief Diversity and Inclusion Officer at Advocate Aurora Health, where she leads the system-wide rollout of diversity and inclusion efforts. She has nearly two decades of development and consulting experience. Previously, Ms. Daniels was Milwaukee's Brady Corporation's Global Director of Organizational Development. She also held employee development positions at the Federal Bureau of Prisons in Washington, D.C. Ms. Daniels serves on the Board of the Betty Brinn Children's Museum and is a Trustee at Mount Mary University. She is active in TEMPO Milwaukee Professional Women's Network and is a Co-Founder and Board member of One MKE, an organization dedicated to addressing cultural divides in the Milwaukee community.

Ms. Eloiza Domingo-Snyder, MS, is the Executive Director of Diversity and Inclusion for Astellas Pharmaceuticals in the Americas. She assumed this role in 2018 with responsibility for developing and implementing a sustainable Diversity and Inclusion strategy that reflects and enhances Astellas' culture and work environment. In her previous role as Senior Director and Deputy Chief Diversity Officer at Johns Hopkins Medicine and The Johns Hopkins Health System Corporation, Eloiza led diversity leadership programs across all of the health system's medical facilities and the Johns Hopkins University School of Medicine. Eloiza holds an M.S. in Higher Education and Student Affairs with a minor in Counseling and concentration in Diversity Education from Indiana University. She is currently earning her doctorate in literacy, language and culture from the University of Maryland Baltimore County.

Ms. Dorcas Lind, MPH, is a Diversity & Inclusion and healthcare communications professional with more than 25 years of experience managing national and global, multi-level staff; ensuring processes are put in place to create efficient, effective teams. After a 15-month consulting engagement, Dorcas joined Montefiore fulltime in June 2018 to build the first D&I offering for the medical center. Through her consultancy, Diversity Health Communications, she achieved success on behalf of healthcare/pharmaceutical companies who have secured a place on the DiversityInc Top 50 Companies list over the past several years. Dorcas obtained a M.P.H. from the University of California at Berkeley Graduate School of Public Health in behavioral science and health education.

Dr. Derek J. Robinson, M.D., MBA, is vice president and chief medical officer for Blue Cross and Blue Shield of Illinois (BCBSIL). In this role, Dr. Robinson provides clinical leadership and strategic oversight to help ensure effective and efficient delivery of quality medical care to more than 8.5 million health plan members. Dr. Robinson, a practicing emergency medicine physician, also serves as the chair of the company's Health Equity Steering Committee, which is responsible for the development and implementation of the company's health equity strategy, including institutionalizing equity across the company's business operations in five states. Prior to BCBSIL, Dr. Robinson was the first physician member of the executive leadership team at the Illinois Health and Hospital Association where he led efforts to improve health care quality and safety for patients across Illinois.

Ms. Cassandra Cantave (Burton), MS, is a Senior Research Advisor for AARP. She has conducted extensive research on issues affecting economically disadvantaged and marginalized populations. Cassandra is passionate about issues that affect women of color, LGBTQ/SGL individuals, young adults, and multicultural populations. She has tackled and helped support advocacy efforts around caregiving, consumer protections, workplace protections, age discrimination, and livable communities. Cassandra is adept at engaging diverse audiences as a lecturer and has an extensive career in the non-profit sector in Washington, DC. Cassandra completed her Master's degree in Sociology from Howard University. She has also obtained her Bachelor's in Sociology from SUNY at Buffalo.

Mr. Joel D. Jackson serves as a subject matter expert and facilitator for several programs at The Village through the Chicago Center for HIV Elimination (CCHE). He is also the University of Chicago–Medicine (UCM) Assistant Director of Inclusion and Training for the Diversity, Inclusion and Equity Department. He coordinates the hospital's cultural competence training strategy and is the lead facilitator of the UCM 18-Hour Cultural Competence Course. Joel received his Bachelor of Arts in 2000 as the first male to major in Women's Studies at Washington University in St. Louis. He also has nearly 20 years of experience working in social justice, facilitating anti-oppression training and serving in the field of HIV prevention.

Ms. Cody McSellers-McCray, MPH, CHES, is the Regional Director, Community Health for AMITA Health, where she provides strategic direction for the operational aspects of the system's community health initiatives and strategies, towards improving health equity. Throughout her career, she has created systems, programs, partnerships and advocated for policies to better the health of under-represented/untapped populations. Previously, she served as Regional Business Development Executive for Health Leads, where she was charged with growing partnerships with health systems, hospitals, FQHC's and health plans in the Midwest and Southeast regions. Cody earned a B.S. in Kinesiology and Master of Public Health degree from Northern Illinois University.

Dr. William Simmons, MD, is Associate Professor with a duel academic appointment at University of Pittsburgh School of Medicine, Department of Anesthesiology and UPMC Presbyterian Shadyside Hospital. Dr. Simmons has spent over 24 years teaching anesthesiology to residents, fellows, medical students and nurse anesthetists and was honored with an excellence in a teaching award by the University of Pittsburgh Medical Students. Dr. Simmons serves as a member of the Physician Inclusion Council which serves both UPMC and the University of Pittsburgh, he chairs an advisory committee in Diversity in the Department of Anesthesiology, co-chairs the Retention Committee for UPMC/PITT. Dr. Simmons is also Immediate Past President at Gateway Medical Society, Inc., and Chair at Journey to Medicine Academic Mentorship Program.

This panel focused on the need for as well as the current issues preventing culturally competent healthcare. Cultural competence is a set of behaviors, attitudes, and policies that enables efficiency in multicultural situations.[10] Regarding the healthcare setting, one panelist asserted that physicians often do not take the time to fully understand each individual patient, with prevents them from fully understanding the environment and behavioral expectation that a patient is facing. This can be an issue with mental health in particular communities, as behavior expectations can prevent emotions from being expressed and people disclosing their issues to a health professional.

Within these issues is internalized stigmas and prejudices against minorities that healthcare professionals may not even realize are being employed. This discrepancy in understanding can lead to inequitable care and patient dissatisfaction. The quality of patient-physician interactions is lower among non-White patients, with the lowest numbers being for Latinos and Asian Americans; these discrepancies have an association with lower overall levels of satisfaction with the healthcare a patient receives.[11] Research has shown that these correlations hold true for the LGBTQIA+ individuals as well. Patients often face structural and personal barriers to healthcare not only due to their sexual and gender identity, but also face a compounding effect if the individual is a member of another marginalized group.[12] A panelist added that members of the LGBTQIA+ community are more likely to be socially isolated and also more likely to be caregivers. Healthcare professionals need to be aware of and take into account these additional burdens in order to provide equitable healthcare.

"The quality of patient-physician interactions is lower among non-White patients, with the lowest numbers being for Latinos and Asian Americans."

Addressing potential solutions to these discrepancies, the panelists began with several "needs" that they would like to see occur in order to avoid future issues. The first explained was the necessity of regularly interacting with individuals that are different than oneself, as the majority of the time in a healthcare setting, there will be differences between the provider and the patient. Panelists also expressed the need for cultural humility and a rejection of any ethnic-centricity that can lead to bias. A healthcare provider also needs the ability to see things from multiple perspectives and have education in the skill set necessary to achieve this from trainings. Another panelist brought-up the need for courage in these trainings; we cannot hide from the history and facts in favor of providing "positive" messaging or we risk the trainings being ineffective.

The panel also discussed situations where patients can be accommodated and others where the provider's beliefs be accommodated. Understanding where a patient comes from and what they are trying to maintain is key in accommodating a patient's request. For example, in religious situations, understanding rules and cultural expectations can aid in ensuring that a patient is comfortable with the care they receive. In these situations, asking questions rather than assuming can show the environment to be an affirming one and allows a patient to feel heard in their concerns. Within this though, the rights of providers also need to be preserved. This can range from dealing with a patient who may have a bias against their provider and accommodating a "tap-out" in non-emergency situations.

"Understanding where a patient comes from and what they are trying to maintain is key in accommodating a patient's request."

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Wednesday, June 24, 2020 | Chicago, IL

The 10th annual Diversity, Inclusion, & Health Equity Symposium is a leading annual, collaborative event focusing on health equity and health disparities in the U.S. The symposium brings together leading healthcare professionals, executives, physicians, patient groups, patients, researchers, academics, clinical trial professionals, and diversity and inclusion advocates to discuss health equity in the life sciences and the health sectors. The symposium focuses on the latest trends, challenges, opportunities in both the marketplace and workplace, with a specific focus on how to best serve an increasingly diverse patient base. We also aim to address the broader health disparity challenges in the U.S., and the symposium equips attendees with the latest insights and ideas. Attendees will learn practical solutions, share perspectives, and meet new industry and marketplace colleagues.

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Equitable Access to Rare Disease Therapies Workshop Executive Summary

On May 23, 2019, the Center for Healthcare Innovation (CHI) held an Equitable Access to Rare Disease Therapies Workshop which took place in Washington D.C. The workshop focused on identifying solutions to the challenges preventing equitable access to rare disease therapies in the United States. This workshop brought together patients, families, patient advocacy groups, biopharmaceutical firms, providers, policymakers, and other NGOs to discuss how to achieve equitable access to care. The panels focused on the latest developments and prominent challenges in accessing novel rare disease treatments, as well as encouraging and accelerating innovation and utilization. In addition, we also discussed the current barriers to care, including delayed access to treatments and drug pricing.

The paradigm shift towards patient-centered care and increasing emphasis on rare diseases highlights the need for innovative treatments and technologies. This executive summary aims to serve as a guide of the ideas and insights regarding the challenges and calls to action in the rare disease community.

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