

September 21, 2021

Congressional Social Determinants of Health Caucus Co-Chairs:

Representative Cheri Bustos

Representative Tom Cole

Representative G.K. Butterfield

Representative Markwayne Mullin

Re: Congressional Social Determinants of Health Caucus – Request for Information

Dear Co-Chairs of the Congressional Social Determinants of Health Caucus:

The Pharmaceutical Research and Manufacturers of America (PhRMA) appreciates the opportunity to comment on your Request for Information (RFI), which seeks feedback on challenges and opportunities related to social determinants of health.

Consistent with our priority of building a more just, equitable health care system, PhRMA believes that diversity, equity, and inclusion are essential to the discovery of new medicines and that people of all ethnic and racial backgrounds should have equitable access to treatment.

PhRMA is taking action to address barriers by 1) promoting policy solutions to improve affordability and equitable access to medicines 2) taking action to support community efforts to address inequities in underdiagnosis and undertreatment, particularly for COVID-19, and 3) improving diversity in clinical trials.

Our comments follow below. Thank you for the opportunity to comment on this important matter. Please feel free to contact Courtney Christian, MPA for any questions about this comment letter.

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September 21, 2021

Re: Social Determinants of Health Caucus RFI

Dear Co-Chairs of the Congressional Social Determinants of Health Caucus:

The Pharmaceutical Research and Manufacturers of America (PhRMA) appreciates the opportunity to comment on your Request for Information (RFI), which seeks feedback on challenges and opportunities related to social determinants of health. We commend the Social Determinants of Health Caucus (the Caucus) for issuing this RFI and look forward to working with you and other stakeholders to address the important issues raised.

Consistent with our priority of building a more just, equitable health care system, PhRMA believes that diversity, equity, and inclusion are essential to the discovery of new medicines and that people of all ethnic and racial backgrounds should have equitable access to treatment.<sup>1</sup> Inequities are often rooted in community-level factors like where we live, work, and play; lack of adequate coverage and access to providers; and systemic racism and discrimination. There are myriad and intersecting systemic social and structural barriers that impede equitable access to medicines, and we believe that one of the most important things Congress could do right now to improve equity in health care access and outcomes would be to improve insurance coverage in a way that makes medicines more accessible and affordable for everyone.

Many patients in the U.S., including those with insurance coverage, face exorbitant out-of-pocket costs for their medicines. For disadvantaged and socioeconomically deprived communities, the eroding value of health insurance can exacerbate delays in diagnosis and access to medicine, further widening disparities in health outcomes.

Yet, proposals currently pending in Congress would be a step backward for many underserved Americans. Members of Congress are considering drug pricing reforms that would do very little to improve affordability and equity for patients who need prescription medicines, and could instead result in less innovation, fewer jobs, and new restrictions on access. Such policies undervalue the preferences, priorities and health care needs of diverse populations that make up the United States.

Government price setting policies being debated in Congress could lead to long-term negative consequences for underserved populations by threatening access to current medicines and denying them access to future medical advances that could significantly improve their lives. Although proponents of so-called government negotiation are eager to downplay these risks, in truth the Congressional Budget Office has opined on multiple occasions that giving the government authority to negotiate in Medicare will only yield greater savings than plans negotiate today if the government is able to exclude or limit access to certain medicines in the

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<sup>1</sup> PhRMA, “Building a Better Health Care System: PhRMA’s Patient-Centered Agenda”  
<https://phrma.org/report/Building-a-Better-Health-Care-System-PhRMAs-Patient-Centered-Agenda>

course of its negotiations. This denial of access to innovations plays out in other countries today that have enacted similar price setting policies. For example, the first transformative CAR-T cancer therapy was available in the United States 7 months before any other country and is still not available in many countries.<sup>2</sup> Many of these countries also rely on flawed models to assess clinical or cost effectiveness that, by design, undervalue lives of vulnerable populations like the severely ill, disabled, or communities of color.

Moreover, many government price setting policies are designed to sit on top of our existing systems, like Medicare Part D. The proposals focus on lowering government spending on covered medicines, but do not prevent health plans from limiting coverage or imposing restrictions on access just as they do today. As a result, patients with chronic conditions may lose access to their current treatments or experience interruptions in care. Economists, investors, and other experts agree price setting policies like the Lower Drug Costs Now Act, also known as H.R. 3, would not directly address the patient affordability problem in the U.S. but instead would have a dramatic impact on reducing investment in research and development of new medicines.<sup>3</sup>

In fact, nearly 400 leading biopharma innovators, investors, and patient advocates recently warned that government price setting in Medicare would devastate the ability to bring new life-saving medicines to market and “immediately halt private funding of drug discovery and development” and “defund R&D for diseases of aging, including Alzheimer’s, osteoporosis, and cancer”.<sup>4</sup> It simply is not the case that the government, through the National Institutes of Health or otherwise, can make up for the reductions in private investment that have been described. The private and public sectors each play a vital role in our biopharmaceutical research ecosystem.

Today, America’s biopharmaceutical companies are on the frontlines of developing treatments and vaccines not just for COVID-19, but also thousands of other debilitating and life-threatening conditions including Alzheimer’s disease,<sup>5</sup> cancers,<sup>6,7</sup> and many other common chronic and rare diseases that disproportionately impact Black and Brown communities.<sup>8,9,10</sup> In 2021, there are 829 medicines in development by biopharmaceutical research companies, all of which are undergoing in-human clinical trials or awaiting review by the Food and Drug Administration

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<sup>2</sup> PhRMA analysis of IQVIA Analytics Link and U.S. Food and Drug Administration (FDA), European Medicines Agency (EMA) and Japan’s Pharmaceuticals and Medical Devices Agency (PMDA) data on new active substances first launched globally between January 2011 and December 2020, April 2021.

<sup>3</sup> Cookson G. H.R.3 is the wrong policy for the wrong problem. Office of Health Economics. 10 September 2021. <https://www.ohe.org/news/hr-3-wrong-policy-wrong-problem>

<sup>4</sup> No Patient Left Behind Sign-On Letter. No Patient Left Behind. September 8, 2021. Available at: <https://nopatientleftbehind.docsend.com/view/a6bxibzxysaeggm3>

<sup>5</sup> 2020 Alzheimer’s disease facts and figures. Alzheimer’s and Dementia. <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068>

<sup>6</sup> Cancer Stat Facts: Prostate Cancer. SEER. <https://seer.cancer.gov/statfacts/html/prost.html>

<sup>7</sup> i Multiple Myeloma Research Foundation. <https://themmrf.org/multiple-myeloma/black-patients/>

<sup>8</sup> National Diabetes Statistics Report 2020. CDC.

<sup>9</sup> Sickle Cell Disease. CDC. <https://www.cdc.gov/ncbddd/sicklecell/data.html>

<sup>10</sup> National Diabetes Statistics Report 2020. CDC.

(FDA).<sup>11</sup> Government price setting policies could halt access to the private capital needed to see such trials through, putting the development of these and future treatments in particular at significant risk.

There's a right way to make medicines more affordable for patients without impeding access or innovation, and PhRMA is willing to do its part. We support reducing insurance barriers to facilitate equal access to prescribed medicines. Practical policies to do this should focus on ensuring affordable coverage options that serve patient needs, such as capping annual patient out-of-pocket spending, lowering cost sharing and making it more predictable, and sharing savings from negotiated rebates directly with patients at the pharmacy counter.<sup>12</sup>

In addition, PhRMA supports policies and practices to help drive durable, systemic change including improving clinical trial diversity; addressing vaccine reluctance; building a diverse health care workforce; addressing underdiagnosis and undertreatment and improving data collection and reporting.<sup>13</sup>

Addressing social determinants of health (SDOH)—including insurance coverage, patient costs, and barriers to access—is key to advancing health equity. PhRMA applauds the Caucus' efforts to improve health outcomes and maximize existing and future Federal investments in eliminating key drivers of health inequities. Our detailed comments on challenges and opportunities related to addressing SDOH follow below.

**i) What specific social determinants of health challenges have you seen to have the most impact on health? What areas have changed most during the COVID-19 pandemic?**

PhRMA recognizes that creating sustainable policies to address SDOH is critical for the advancement of health equity, particularly for communities of color. Addressing health inequities not only requires reducing insurance barriers and other policy changes, but also identifying barriers to care that are specific to a given community, which requires connecting and learning from communities who are experiencing inequities, especially in areas where disparities have been exacerbated by COVID-19.<sup>14</sup> Recognizing the importance of community-led efforts to understand and impact inequities, PhRMA and its member companies have been actively

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<sup>11</sup> Number of medicines obtained through public government and industry sources, and the Springer “AdisInsight” database; current as of June 8, 2021

<sup>12</sup> PhRMA, “Building a Better Health Care System: PhRMA's Patient-Centered Agenda” (available at: <https://phrma.org/report/Building-a-Better-Health-Care-System-PhRMAs-Patient-Centered-Agenda>).

<sup>13</sup> PhRMA, “Building a Better Health Care System: PhRMA's Patient-Centered Agenda” (available at: <https://phrma.org/report/Building-a-Better-Health-Care-System-PhRMAs-Patient-Centered-Agenda>).

<sup>14</sup> Gracia JN. COVID-19's Disproportionate Impact on Communities of Color Spotlights the Nation's Systemic Inequities. *Journal of Public Health Management and Practice* 2020; 26(6):518-521. doi: 10.1097/PHH.0000000000001212.

working to build partnerships in underserved communities to improve access to COVID-19 testing, vaccinations, and treatments to end the pandemic.<sup>15,16</sup>

Earlier this year, PhRMA conducted focus groups to understand the overarching factors inhibiting health equity. Focus group members expressed that addressing social determinants of health, such as systemic racism and bias, are challenges to reducing disparities. Recent research among a nationally representative cohort of Americans found that 32 percent of Black Americans, 20 percent of Latino Americans, and 23 percent of Native Americans stated they had been discriminated against when seeking health care because of their race or ethnicity.<sup>17</sup> In addition, multiple studies have revealed that discrimination is associated with increased incidence of mental health disorders,<sup>18,19</sup> hypertension,<sup>20</sup> and all-cause mortality.<sup>21</sup> This evidence and the expressed challenges faced by focus group members demonstrate the harms of discrimination, a key social determinant, on health and health outcomes. In addition, focus group members expressed that authentic engagement with communities is critical to solving health inequities, as well as addressing discrimination and racism in health care.

Furthermore, other drivers of health inequities, such as disparities in income and access to care are important determinants of health. Since the start of the COVID-19 pandemic, roughly one-in-four Americans have been laid off or lost their job due to the pandemic. Lower-income workers have borne the brunt of this loss.<sup>22</sup> Financial insecurity during the pandemic has affected lower-income workers' ability to pay for necessities, with 44 percent stating that they have used money from savings/retirement to pay bills, and 35 percent stating that they have received food from a food bank/organization since the start of the pandemic. Due to concerns about the pandemic, 41

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<sup>15</sup> PhRMA's press release. Five Steps to Urgently Advance COVID-19 Vaccine Equity. 19 May 2021. Gracia, J. N. (2020). COVID-19's Disproportionate Impact on Communities of Color Spotlights the Nation's Systemic Inequities. *Journal of Public Health Management and Practice*, 26 (6), 518-521. doi: 10.1097/PHH.0000000000001212.

<sup>16</sup> PhRMA's request for information. PhRMA CAREs Grant: Addressing Inequities in Access to COVID-19 Testing, Therapeutics, and Vaccines. 3 May 2021. <https://phrma.org/coronavirus/phrma-cares-grant-addressing-inequities-in-access-to-covid19-testing-therapeutics-and-vaccines>

<sup>17</sup> Discrimination in America: Final Summary. Robert Wood Johnson Foundation. Jan 2018.

<https://www.rwjf.org/en/library/research/2017/10/discrimination-in-america--experiences-and-views.html>

<sup>18</sup> Gee GC, Spencer M, Chen J, Yip T, Takeuchi DT. 2007. The association between self-reported racial discrimination and 12-month DSM-IV mental disorders among Asian Americans nationwide. *Soc. Sci. Med.* 1982 64: 1984-96

<sup>19</sup> Pilver CE, Desai R, Kasl S, Levy BR. 2011. Lifetime discrimination associated with greater likelihood of premenstrual dysphoric disorder. *J. Women's Health* 20: 923-31

<sup>20</sup> Dolezsar CM, McGrath JJ, Herzig AJ, Miller SB. 2014. Perceived racial discrimination and hypertension: a comprehensive systematic review. *Health Psychol.* 33:20-34

<sup>21</sup> Farmer H, Wray L, Thomas J, Race and Everyday Discrimination on Mortality Risk in the Health and Retirement Study, *Innovation in Aging*, Volume 2, Issue suppl\_1, November 2018, Page 649, <https://doi.org/10.1093/geroni/igy023.2421>

<sup>22</sup> Parker K, Minkin R, Bennet J. Economic Fallout From COVID-19 Continues to Hit Lower-Income Americans the Hardest. Pew Research Center. 24 September 2020. <https://www.pewresearch.org/social-trends/2020/09/24/economic-fallout-from-covid-19-continues-to-hit-lower-income-americans-the-hardest/>

percent of adults have avoided or delayed routine or emergency/urgent care.<sup>23</sup> The prevalence of delaying or avoiding care is higher among Black (60 percent higher) and Hispanic (50 percent higher) adults than non-Hispanic White adults. These disparities demonstrate that the pandemic has had harmful effects on the social, economic, and health care-related outcomes among lower-income and race/ethnic-diverse groups.

**ii) What types of gaps in care, programs, and services serve as a main barrier in addressing SDOH in the communities you serve? What approaches have your organization, community, Tribal organization, or state taken to address such challenges?**

Research clearly shows that social determinants of health impact life-long health care outcomes.<sup>24</sup> Within the communities we serve, notable barriers to equity include an insurance system that too often fails to provide ready and affordable access to innovative medicines; resistance to health care interventions including vaccine hesitancy; and a historic lack of diversity in clinical trials.

*Promoting policy solutions to improve affordability and equitable access to medicines*

While we have made strides in reducing the number of Americans without insurance over the last decade, cost remains a barrier for many—particularly for medicines—even among those with insurance. Historically disadvantaged communities are disproportionately affected by poor insurance coverage due to multi-generational wealth inequities attributable to the effects of racism and the ability to have wealth.<sup>25</sup> Poor insurance coverage reduces access to care, including the ability to receive a prescription from a health care provider and fill it at the pharmacy. Underinsurance and high out-of-pocket costs should not be barriers to accessing prescribed medicines known to be effective at preventing or treating serious illness.

Right now, many of the sickest patients and lower-income communities are burdened with a disproportionate share of their health care costs. Through an endless web of high deductibles, expanded cost sharing, coverage exclusions and narrow formularies, insurers are increasingly standing between patients and the care they need. Patients need lower out-of-pocket costs without reducing health care choice, quality, or access.

We need to rethink insurance to reduce cost barriers for patients that can result in unequal access to medicines in both government health care programs and the commercial market. PhRMA is

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<sup>23</sup> Czeisler MÉ, Marynak K, Clarke KE, et al. Delay or Avoidance of Medical Care Because of COVID-19–Related Concerns — United States, June 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:1250–1257. DOI: <http://dx.doi.org/10.15585/mmwr.mm6936a4>

<sup>24</sup> Reno R, Warming E, Zaugg C, Marx K, Pies C. Lessons Learned from Implementing a Place-Based, Racial Justice-Centered Approach to Health Equity. *Matern Child Health J.* 2021 Jan;25(1):66-71. doi: 10.1007/s10995-020-03076-1. Epub 2020 Nov 26. PMID: 33242209.

<sup>25</sup> William Darity Jr. et al., *What We Get Wrong About Closing the Racial Wealth Gap* (Duke University, Samuel Dubois Cook Center on Social Equity, Apr. 2018); Dettling et al., “Recent Trends in Wealth-Holding,” 2017; Kochar and Cilluffo, “How Wealth Inequality Has Changed,” 2017; and Lerner, “One Home, A Lifetime of Impact,” 2020.

willing to do its part. As an industry, we support ways to enhance competition to drive lower costs. Our companies also individually continue to make assistance available to those who are having trouble accessing and affording their medicines.<sup>26</sup>

Medicare Part D could work better and be made fairer by improving affordability and predictability for beneficiaries who face high out-of-pocket costs for their medicines. Improvements to Part D must be done the right way, with targeted and measured reforms, such as:

- **Cap annual out-of-pocket costs.** More than 1.5 million non-low-income beneficiaries incurred out-of-pocket spending high enough to reach the catastrophic limit in 2019, more than triple the number in 2007.<sup>27</sup> On average, beneficiaries who reached catastrophic coverage in 2015 had out-of-pocket expenses greater than \$3,000. Establishing a maximum annual limit on beneficiary out-of-pocket spending would provide a true catastrophic benefit to protect the sickest patients.
- **Lower cost-sharing and make it more predictable.** In recent years, it has become common for Part D plans to charge coinsurance rather than flat copayments for medicines to treat complex conditions. This can translate into higher and less predictable costs for patients. The “standard” Part D benefit today calls for cost sharing of 25 percent during the initial coverage phase. Lowering the standard Part D benefit coinsurance for non-low-income patients would have a meaningful impact on their out-of-pocket costs—whether or not they reach the annual out-of-pocket cap. Further, due to the current Part D benefit structure, many patients with complex conditions face significantly higher costs at the beginning of the year, although, high out-of-pocket costs could happen at any point in the year depending on when a patient starts their prescription. We should allow spreading (or “smoothing”) of out-of-pocket costs over the course of the year to make their monthly expenses more predictable.
- **Share savings at the pharmacy counter.** The rebates and discounts pharmaceutical manufacturers negotiate with Part D health insurance plans often are not directly used to lower beneficiary out-of-pocket costs. Instead, coinsurance and deductibles are typically based on a brand medicine’s undiscounted list price. A recent analysis found that 92 percent of Part D beneficiaries’ out-of-pocket spending is based on the list price rather than the discounted price their insurer gets. Charging higher cost sharing for sick patients taking brand medicines and using the rebate savings to lower premiums for healthier enrollees is not how insurance is supposed to work.<sup>28</sup> We must ensure these savings are passed on to seniors and people with disabilities at the pharmacy counter.

Changes also can be made in the commercial market to help insurance work better when people need it most. We support the following improvements in the private insurance market:

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<sup>26</sup> PhRMA’s Building a Better Health Care System Agenda. [https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/A-C/Better-Way\\_Proactive-Agenda1.pdf](https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/A-C/Better-Way_Proactive-Agenda1.pdf)

<sup>27</sup> Cubanski J, Newman T, Damico A. Millions of Medicare Part D Enrollees Have Had Out-of-Pocket Drug Spending Above the Catastrophic Threshold Over Time. Kaiser Family Foundation. July 2021

<sup>28</sup> PhRMA analysis of IQVIA data, 2021. <https://catalyst.phrma.org/out-of-pocket-trends-in-medicare-part-d-showing-rising-costs-for-seniors> .

- **Cover more medicines from day one.** Insurers are increasingly requiring people to pay high deductibles before receiving coverage of their medicines. This can lead to people rationing their medicine or not taking it at all, suffering devastating consequences to their health. People managing chronic health conditions should not have to pay a deductible for those medicines at the pharmacy counter. Instead, they should have at least some of their medicines covered by their insurance from day one.
- **Make cost sharing more predictable.** High and unpredictable cost sharing is a barrier to prescription medicine access, especially for patients with chronic, disabling or life-threatening conditions who shoulder the largest share of the burden. Insurers' increasing use of coinsurance – where patients are charged a portion of the full list price of a medicine – can leave patients with sticker shock at the pharmacy counter. One potential solution is to encourage the use of fixed-dollar copays instead of coinsurance. Placing a limit on the maximum amount a patient will be asked to pay per prescription, per month and/or annually would also help.
- **Make coupons count.** Due to high out-of-pocket costs set by health plans, people are increasingly turning to manufacturer cost sharing assistance to help them afford their medicines. In some cases, health insurance companies do not allow the assistance manufacturers provide to patients to count toward deductibles or other out-of-pocket limits, meaning people could be paying thousands more at the pharmacy than they should be. We need to end this practice and ensure that people get the full benefit of the programs meant to help them afford their medicines.
- **Share the savings.** Rebates and discounts that pharmaceutical companies pay to health insurance companies, middlemen like pharmacy benefit managers, the government and others reduce the list prices of brand medicines by 40 percent, on average. Just like in Medicare Part D, these rebates and discounts often don't reach commercially insured patients at the pharmacy counter, particularly for patients with high deductibles and coinsurance. If insurance companies and middlemen don't pay the full price for medicines, patients shouldn't either. These rebates and discounts should be shared directly with patients at the pharmacy counter.

*Taking action to support community efforts to address inequities in underdiagnosis and undertreatment*

In April 2019, PhRMA created the Collaborative Actions to Reach Equity (CAREs) grant program, which has since awarded nearly \$350,000 to community organizations, institutions, and individuals who have a mission to advance health equity. The PhRMA CAREs grant program aims to address health inequities through partnership with community-led organizations to support local and national activities and research. With funding provided by the PhRMA CAREs grant program, grantees nationwide are driving meaningful change on-the-ground by addressing pressing social determinants of health issues, such as maternal mortality, access to COVID-19

treatments and vaccines, implicit bias in seeking health care, and disparities in medication use/access.

For example, Bridge-Pamoja, one CAREs grant recipient, is a network of faith-based leaders and culturally specific organizations dedicated to addressing unique needs of African and African American communities in the Portland, Oregon area through grassroots and community-based efforts. To combat the COVID-19 pandemic, Bridge-Pamoja aims to break down barriers to the uptake of COVID-19 vaccines within local African and African American communities using a three-pronged approach: 1) partnering with state officials to track how many Africans and African Americans successfully complete doses of COVID-19 vaccines; 2) monitoring how the state government partners with Black-led organizations (including houses of worship) to perform outreach to the African and African American communities regarding COVID-19 vaccination; and 3) hosting virtual forums with Black community and faith leaders to address the successes and challenges of the state's COVID-19 vaccination outreach process.<sup>29</sup> Through these efforts, Bridge-Pamoja has helped to create an environment that fosters relationships of trust through reliable messengers.

This is just one example of the type of impact on-the-ground organizations can have to improve health equity—and how PhRMA aims to support that work. We would welcome the opportunity to provide Caucus members and staff with additional information about our CAREs grant program.

### *Improve diversity in clinical trials*

PhRMA has also made a concerted effort to better understand industry practice and ongoing efforts among member companies, health care providers, and community stakeholders to enhance clinical trial diversity. The biopharmaceutical industry sees furthering clinical trial diversity as a critical component of helping to ensure health equity for all communities and helping study populations better reflect intended treatment populations. Unfortunately, there is no silver bullet fix. Documented research and real-world experiences point to several specific challenges:

- Real mistrust from experiments like the Tuskegee Syphilis Study, Henrietta Lacks, and current interactions with the health system have led many to be wary of clinical trials
- Limited awareness of trial opportunities among potential participants
- Barriers preventing patient access to trials, like lack of childcare, consistent transportation, or broadband/internet access needs
- A lack of existing clinical trial sites in underrepresented communities

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<sup>29</sup> PhRMA Covid-19 Collaborative Actions to Reach Equity (CAREs) Grant: Spurring Ideas for a More Equitable Future Available at: [https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/A-C/COVID-19\\_Community\\_Action\\_Health\\_Equity\\_Grant\\_RFP.pdf](https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/A-C/COVID-19_Community_Action_Health_Equity_Grant_RFP.pdf)

Our efforts over the last 18 months have helped us clearly identify and articulate external barriers to clinical trial participation and opportunities to build community awareness, remove access and participation barriers, increase access to ready clinical trial sites in underserved communities, train investigators and clinical support staff, and build trust. Industry has taken a stakeholder partnership and community driven approach to this effort, including issuing of racial justice principles to show our commitment to address systemic issues that deter Black and Brown communities from participating in clinical trials<sup>30</sup> and our voluntary member company commitment to Principles on Clinical Trial Diversity,<sup>31</sup> which address building trust, reducing patient barriers to clinical trial access, and using real-world data to enhance information on diverse populations beyond product approval. As part of this effort, PhRMA recently convened over 150 organizations to address key barriers to participation and to work toward piloting a community-based infrastructure focused on clinical trial diversity.

**iii) Is there a unique role technology can play to alleviate specific challenges (e.g., referrals to community resources, telehealth consultations with community resource partners, etc.)? What are the barriers to using technology in this way?**

Digital technologies are creating new opportunities to modernize health care and empower patients to make more informed decisions about their health. There are also opportunities for digital tools to help address health outcomes by reducing medication nonadherence, which costs the health care system hundreds of billions of dollars each year and can disproportionately hurt underserved populations.<sup>32</sup> For example, among Medicare Part D beneficiaries, the odds of adherence to antihypertensive medications were 47 percent and 42 percent lower among Black and Hispanic beneficiaries, respectively, compared to Whites.<sup>33</sup> In addition, among a population of more than 14,000 privately insured individuals with hepatitis C, the odds of initiating direct-acting antiviral agents were 20 percent and 30 percent lower for Hispanic and Black patients, respectively, compared to Whites.<sup>34</sup> Lower medication adherence among Black and Brown communities is not limited to one or a few health conditions—these disparities have been demonstrated in communities of color across a wide array of diseases, and among people with all types of insurance coverage. Evidence has shown that the downstream consequences of

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<sup>30</sup> PhRMA’s Racial Justice Principles. PhRMA. Available at: [https://www.phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/DEI/DEI\\_PrintAd\\_FINAL.pdf](https://www.phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/DEI/DEI_PrintAd_FINAL.pdf)

<sup>31</sup> Principles on Conduct of Clinical Trials Communication of Clinical Trial Results. PhRMA. [https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/P-R/PhRMAPrinciples-of-Clinical-Trials-FINAL.pdf?\\_gl=1\\*1bli4xc\\*\\_gcl\\_aw\\*R0NMLjE2MzE1NDYzMzYuRUFJYUIRb2JDaE1JdlIIIRzNKXzg4Z0lWcWZfSUNoMF93QU5SRUFBWUFTQUFFZ0tmUFBEX0J3RQ..](https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/P-R/PhRMAPrinciples-of-Clinical-Trials-FINAL.pdf?_gl=1*1bli4xc*_gcl_aw*R0NMLjE2MzE1NDYzMzYuRUFJYUIRb2JDaE1JdlIIIRzNKXzg4Z0lWcWZfSUNoMF93QU5SRUFBWUFTQUFFZ0tmUFBEX0J3RQ..)

<sup>32</sup> Prescriptions for a Healthy America. A Treatable Problem: Addressing Medication Nonadherence by Reforming Government Barriers to Care Coordination.” October 2017. <https://static1.squarespace.com/static/589912df1b10e39bd04eb3ab/t/59f0e439edaed84e6822d9bd/1508959306380/P4HA+WhitePaper+E-DigitalFinal+1017.pdf>

<sup>33</sup> Holmes HM, Luo R, Hanlon JT, Elting LS, Suarez-Almazor M, Goodwin JS. Ethnic disparities in adherence to antihypertensive medications of Medicare Part D beneficiaries. *J Am Geriatr Soc.* 2012;60:1298–1303.

<sup>34</sup> Marcus JL, Hurley LB, Chamberland S, et al. Disparities in Initiation of Direct-Acting Antiviral Agents for Hepatitis C Virus Infection in an Insured Population. *Public Health Rep.* 2018;133(4):452-460.

medication nonadherence include increased health care costs,<sup>35</sup> poor health outcomes,<sup>36,37</sup> and increased risk of mortality.<sup>38</sup>

Digital tools, such as remote patient monitoring or telehealth visits, can be used to increase access to quality care for patients who may have challenges accessing care in more traditional ways. These tools can improve adherence by decreasing patient burden by making it easier for patients to track their dosing schedules, remember when to take their medications, and allow them to easily share relevant medical information, consistent with applicable legal frameworks, with their health care provider(s) to inform necessary regimen changes. The Caucus should encourage the Department of Health and Human Services (HHS) to engage with stakeholders across the health care system to ensure we are harnessing the full potential of digital health tools and addressing potential coverage and access barriers related to their adoption and use. Exploring opportunities and barriers in use of digital health tools should consider the potential for unintended impacts and biases. Of note, multiple reports link certain artificial intelligence (AI) and clinical algorithms within medical technology to potential racial discrimination.<sup>39</sup> For example, there are concerns that the use of race/ethnicity in the Vaginal Birth After Cesarean (VBAC) calculator, a clinical tool to estimate the likely success of vaginal birth after cesarean delivery, leads to racial disparities in cesarean birth deliveries, with Black women being more likely than White women to be offered cesarean deliveries, which are associated with poorer birthing outcomes.<sup>40</sup> This issue is potentially alarming given that maternal mortality is three to four times higher among Black women as compared to White women.<sup>41</sup> We recommend that the Caucus support efforts and activities to understand the extent of discriminatory practices or unintended biases with use of technology/data.

At the same time, many underserved communities may be hesitant to adopt new technologies due to concerns about misuse and distrust. Therefore, we suggest that the Caucus also work with experts in community-based research/advocacy to ensure that the concerns of underserved

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<sup>35</sup> Sokol MC, McGuigan KA, Verbrugge RR, Epstein RS. Impact of medication adherence on hospitalization risk and healthcare cost. *Med Care*. 2005 Jun;43(6):521-30. doi: 10.1097/01.mlr.0000163641.86870.af. PMID: 15908846.

<sup>36</sup> Bansilal S, Castellano JM, Garrido E, Wei HG, Freeman A, Spettell C, Garcia-Alonso F, Lizano I, Arnold RJ, Rajda J, Steinberg G, Fuster V. Assessing the Impact of Medication Adherence on Long-Term Cardiovascular Outcomes. *J Am Coll Cardiol*. 2016 Aug 23;68(8):789-801. doi: 10.1016/j.jacc.2016.06.005. PMID: 27539170.

<sup>37</sup> Choudhry NK, Glynn RJ, Avorn J, Lee JL, Brennan TA, Reisman L, Toscano M, Levin R, Matlin OS, Antman EM, Shrank WH. Untangling the relationship between medication adherence and post-myocardial infarction outcomes: medication adherence and clinical outcomes. *Am Heart J*. 2014 Jan;167(1):51-58.e5. doi: 10.1016/j.ahj.2013.09.014. Epub 2013 Oct 17. PMID: 24332142.

<sup>38</sup> Khunti K, Seidu S, Kunutsor S, Davies M. Association Between Adherence to Pharmacotherapy and Outcomes in Type 2 Diabetes: A Meta-analysis. *Diabetes Care*. 2017 Nov;40(11):1588-1596. doi: 10.2337/dc16-1925. Epub 2017 Aug 11. PMID: 28801474.

<sup>39</sup> Kent C. A Race to the Bottom: How AI Encodes Racial Discrimination within Medicine. *Medical Technology*. [https://medical-technology.nridigital.com/medical\\_technology\\_sep20/ai\\_racial\\_discrimination\\_medicine](https://medical-technology.nridigital.com/medical_technology_sep20/ai_racial_discrimination_medicine)

<sup>40</sup> Vyas DA, Jones DS, Meadows AR. Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator. *Women's Health Issues*; 2019; 29 (3). <https://doi.org/10.1016/j.whi.2019.04.007>

<sup>41</sup> Reproductive Health. Center's for Medicare and Medicaid. <https://www.cdc.gov/reproductivehealth/drh/about-us/index.htm>. Accessed September 7, 2021.

communities are recognized and addressed in the planning and implementation of digital health tools in diverse communities.

**iv) How could federal programs such as Medicaid, CHIP, SNAP, WIC, etc. better align to effectively address SDOH in a holistic way? Are there particular programmatic changes you recommend?**

The Federal government should take a leadership role in advancing health equity, including requiring Federal health care agencies to assess whether current and proposed policies will support the goal of reducing disparities. PhRMA supports efforts to advance health equity, particularly in Federal health care programs<sup>42</sup> and we commend the Administration for issuing its *Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*.<sup>43</sup> Programmatic changes to address SDOH in a holistic way among Federal programs include:

*Ensuring maximum uptake of current programs.* It is critical that Federal agencies ensure that current Federal programs (e.g., CHIP, SNAP, WIC) are utilized by all who are eligible. We recommend that the Caucus support evaluations of the burdens (e.g., health literacy, limited access to internet, lack of transportation, and paid time off) that present challenges to enrolling in WIC, SNAP, and Head Start programs and prevent eligible individuals from receiving benefits. In addition, it has long been the case that take-up in the Medicare Part D low-income subsidy (LIS) has lagged well behind LIS eligibility. For example, in 2011, only 35 percent of beneficiaries who were eligible for the LIS and who were not auto-enrolled applied for and received the LIS.<sup>44</sup> PhRMA recommends that the Caucus study whether opt-in requirements for Federal programs, such as the LIS, may advance equity and consider potential alternatives.

*Advancing sharing of disparities data.* Federal programs that serve lower-income populations can help to ensure that SDOH data are efficiently shared across Federal programs. PhRMA recommends that Federal agencies test approaches to linking eligibility and enrollment data across programs such as WIC, SNAP and Head Start. In addition, disparate agencies may be given incentives to build the infrastructure to share SDOH and race/ethnicity data across the WIC, SNAP, and Head Start programs.

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<sup>42</sup> PhRMA's comments. RE: Request for Information - Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government. Office of Management and Budget. 7 July 2021. Available at: [https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/D-F/FINAL-070621\\_PhRMA-Response\\_OMB-RFII.pdf](https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/D-F/FINAL-070621_PhRMA-Response_OMB-RFII.pdf)

<sup>43</sup> Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. Executive Order 13958. <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/>

<sup>44</sup> Shoemaker JS, Davidoff A, Stuart B, *et al.* Eligibility and Take-up of the Medicare Part D Low-Income Subsidy. *Inquiry Journal*. Fall 2012. Available at: [https://journals.sagepub.com/doi/pdf/10.5034/inquiryjrnl\\_49.03.04](https://journals.sagepub.com/doi/pdf/10.5034/inquiryjrnl_49.03.04)

*Improving quality measures to better account for equity.* Existing quality and cost measures should be evaluated to ensure they do not mask and/or worsen health disparities that lead to care stinting and should be appropriately stratified or adjusted to recognize population differences. PhRMA applauds efforts by the Centers for Medicare & Medicaid Services (CMS) to incorporate health equity into the Medicare Quality Payment Program, as proposed in the RFI “Closing the Health Equity Gap in CMS Clinician Quality Programs,”<sup>45</sup> and we support CMS’ efforts to bridge the equity gap through future potential stratification of quality measures in the Merit-based Incentive Payment System (MIPS) program.<sup>46</sup> In these efforts, we recommend that stakeholders consider the potential unintended consequences of adjusting performance scores directly and avoid masking true quality of care and outcomes for socially at-risk populations through statistical adjustments. In addition, PhRMA supports the consideration of adjusting performance-based payments based on disparities in patient populations to ensure providers are not unfairly impacted and disincentivized to provide high-quality care to vulnerable patients. PhRMA encourages the development of quality measures that assess vulnerable patient populations’ abilities to access screening, diagnostics, and treatment, and which consider accessibility to care.

**v) Are there any non-traditional partners that are critical to addressing SDOH that should be better aligned with the health sector to address SDOH across the continuum from birth through adulthood? What differences should be considered between non-health partners for adults’ social needs vs children’s social needs?**

Empowering non-traditional, community-based partners to align with the health sector is key to addressing SDOH across the continuum from birth to adulthood. PhRMA recommends considering the following in these efforts:

*Engage community-based organizations and leaders.* The Caucus should consider encouraging consistent engagement between Federal agencies, community-based organizations, and leaders in the development and evaluation of programs, policies, rules, processes, and operations relevant to addressing health inequities. Community-based stakeholders understand the specific needs of communities, which is crucial for successfully designing and implementing outreach efforts to engage the underserved. The Federal government also might consider offering incentives to community-based organizations currently serving as partners to increase recruitment and engagement of underserved communities. Recreational centers, faith-based and religious centers,

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<sup>45</sup> Medicare Program; CY 2022 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment Policies; Medicare Shared Savings Program Requirements; Provider Enrollment Regulation Updates; Provider and Supplier Prepayment and Post-Payment Medical Review Requirements. Federal Registrar. Proposed Rule 86 FR 39104.

<sup>46</sup> PhRMA’s comments. RE: Request for Information – Closing the Health Equity Gap in CMS Quality Programs in Medicare FY 2022 Inpatient Psychiatric Facilities Prospective Payment System and Quality Reporting Updates for Fiscal Year Beginning October 1, 2021. Centers for Medicare and Medicaid. Available at: <https://www.phrma.org/Equity/Comments-on-CMS-Request-for-Information-on-Closing-the-Health-Equity-Gap-in-CMS-Quality-Programs>

and other local organizations can recommend and implement consistent approaches that are relevant and culturally sensitive to community members. For engagement related to health care policies, the Caucus also should consider engaging with relevant disease-specific provider and/or patient groups.

*Implementing strategies to learn from communities on engagement practices.* To meaningfully engage with underserved communities, we recommend that the Caucus and Federal entities seek community feedback. For example, surveys may be deployed with the aim of increasing understanding of the timing, frequency, and modalities of methods to improve engagement on potential Federal SDOH programs. PhRMA would welcome the opportunity to assist the Caucus by facilitating discussions with community leaders and experts to identify best practices for community engagement.

**vi) What opportunities exist to better collect, understand, leverage, and report SDOH data to link individuals to services to address their health and social needs and to empower communities to improve outcomes?**

A robust, interoperable data infrastructure that includes consistent measures of health outcomes associated with race, ethnicity, language, and social determinants of health is imperative to assess and make progress toward equality and reducing disparities in care.<sup>47,48</sup>

Key opportunities to improve SDOH data to improve health outcomes include promoting standards in the collection and reporting of data that can be applied across the health system, using granular definitions to reflect diversity within broad categories of race and ethnicity, collecting data in a culturally sensitive manner, and safeguarding against misuse of personally identifiable data.

We recommend that improvements in data collection and reporting involve strong engagement with experts and community leaders (e.g., HBCUs and community health centers), and patients themselves to understand and test which SDOH data are most important to collect and how to collect them. We also encourage efforts to collect and use health data to consider the intersection between different social and demographic factors. Many populations experience more than one source of disadvantage at a time which can have multiplicative impacts on an individual's life

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<sup>47</sup> COVID-19 shows why united action is needed for more robust international health architecture. World Health Organization. 30 March 2021. <https://www.who.int/news-room/commentaries/detail/op-ed---covid-19-shows-why-united-action-is-needed-for-more-robust-international-health-architecture>

<sup>48</sup> Statement by HHS Secretary Xavier Becerra on the President's FY 2022 Discretionary Funding Request. CMS.gov. 9 Apr 2021. <https://www.hhs.gov/about/news/2021/04/09/statement-hhs-secretary-xavier-becerra-presidents-fy-2022-discretionary.html>

experiences.<sup>49</sup> Finally, we also recommend that investment in improving data infrastructure consider addressing interoperability of health data systems to promote data sharing and reporting and reduce provider burden.

Additionally, there are opportunities to leverage existing data to better inform health care use and outcomes across important subpopulations, particularly as they relate to health disparities. For example, CMS publicly reports select information to inform health disparities among the Medicare and Medicaid populations that could be readily expanded to better understand inequities in diagnosis and treatment by adding measures of recommended screenings and use of medicines.

Additional considerations to improve data collection and reporting can be found in the appendix.

**vii) Which innovative state, local, and/or private sector programs or practices addressing SDOH should Congress look into further that could potentially be leveraged more widely across other settings? Are there particular models or pilots that seek to address SDOH that could be successful in other areas, particularly rural, tribal or underserved communities?**

In the wake of the COVID-19 pandemic, PhRMA realized that one way we can be a part of the solution to address social determinants of health is by providing grants to community-driven organizations to advance health equity. PhRMA's CAREs grant program funds organizations that serve communities on-the-ground and aims to support the identification of community-led best practices that can be leveraged more widely and across other settings<sup>50</sup> These organizations are uniquely positioned to address SDOH by identifying local issues that may exacerbate inequities.

**viii) How can Congress best address the factors related to SDOH that influence overall health outcomes in rural, tribal and/or underserved areas to improve health outcomes in these communities?**

To effectively address social determinants of health that influence health outcomes at a national level, PhRMA proposes that Congress take a multi-faceted approach. Our recommendations include the following:

Empower community-based organizations and leaders to be partners to engage the community and develop/implement SDOH programs. Community-based organizations are integrated with and understand the specific needs of the communities they serve, which is critical

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<sup>49</sup> Nick G, Schloss K, Lekas HM, et al. A Social Determinants Perspective of the Intersection of Ageism, Racism, and Social Isolation During COVID-19. Behavioral Health News. Jan 1, 2021. Available at: <https://behavioralhealthnews.org/a-social-determinants-perspective-of-the-intersection-of-ageism-racism-and-social-isolation-during-covid-19/>

<sup>50</sup> PhRMA COVID-19 Collaborative Actions to Reach Equity (CAREs) Grant: Spurring Ideas for a More Equitable Future. April 2020. <https://phrma.org/coronavirus/phrma-health-equity-roundtable-announces-cares-grants>

to successfully engaging and reaching underserved areas. These organizations can recommend approaches most likely to resonate with their communities.

Work with community-based organizations to plan implementation strategies for SDOH programs. Community-based organizations understand how to effectively reach rural, Tribal and/or underserved communities and are in the best position to assist with outreach and data collection regarding implementation of SDOH programs.

Measure progress on health equity. As Congress continues to pursue the goal of advancing equity throughout the Federal government, as specified in the January 2021 Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,<sup>51</sup> it should ensure that progress is appropriately measured. We propose that Congress focus on SDOH and measure progress through equity evaluations, specifically process and outcomes evaluations. Process evaluations may include conducting surveys and other qualitative research within rural, Tribal, and underserved communities to gain feedback on the execution of activities to address SDOH in local communities. We also suggest that the Caucus and related Federal agencies conduct outcomes evaluations, which focus on progress on critical areas, such as reducing disparities in mortality, under-treatment, and disease; increased partnerships with diverse community-based organizations to address SDOH and inequities; and advancing the inclusion of patient perspectives within planned activities and programs. We recommend that plans for equity assessments should be included in congressional SDOH initiatives to ensure that funds and future efforts are put toward programs and initiatives that will have the greatest impact on improving health for underserved communities.

Thank you for the opportunity to comment on this important matter. PhRMA looks forward to continuing a dialogue with the Caucus regarding challenges and opportunities related to social determinants of health. If you have any questions, you may reach Courtney Christian at [cchristian@phrma.org](mailto:cchristian@phrma.org) or Jacquelyn McRae at [jmcrac@phrma.org](mailto:jmcrac@phrma.org).

Sincerely,

Courtney Christian, MPA

Jacquelyn McRae, PharmD, MS

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<sup>51</sup> The White House, “Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,” available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/>.

## **Appendix. Recommendations for improvements in health equity data collection and reporting**

Promote collection of robust race/ethnicity and SDOH data in an ethical manner and consistent with legal requirements: While standards exist for the collection and reporting of race, ethnicity, language, sex, and disability data in all publicly funded national administrative files and health surveys, these standards do not apply to many other reporting entities at the Federal, state, and local levels, including administrative, billing, and medical records.<sup>52</sup> Additionally, current Federal standards for race/ethnicity data are not sufficiently granular to reflect diversity -- and therefore health disparities -- for smaller underrepresented communities within broad categories of race and ethnicity.<sup>53</sup> PhRMA suggests that Federal regulators consider testing, piloting, and facilitating activities to generate standardized, granular data on ethnically diverse populations in Federal health care programs, so that data representing diversity across a broad range of cultures, backgrounds and lived experiences can be synthesized.<sup>54,55</sup> At the same time, there is limited information on SDOH available in administrative health care claims data. A recent study found that among the 33 million Medicare fee-for-service beneficiaries in 2017, just 1.4 percent had claims with codes related to social determinants of health.<sup>56</sup> The lack of robust data collection on SDOH in Federal, state, and local programs decreases the ability to track health outcomes linked to social determinants.

Although PhRMA strongly supports more robust collection of data, we recognize that increased surveillance and monitoring is not without potential harms to communities. For example, many disadvantaged communities have legitimate fears of sharing personal information due to negative potential consequences.<sup>57</sup> The collection of data should serve to improve health care programs for underserved communities, not provide a means for discrimination for harming individuals. We recommend that the Caucus consult engagement experts to test and implement safeguarding of data elements, ensuring that personally identifiable information remains protected throughout the process. In addition, we recommend that the Caucus engage with experts to test and pilot strategies to mitigate against use of patient information that can potentially negatively impact patient access or care. For example, some artificial intelligence algorithms rely on demographic

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<sup>52</sup> Office of Management and Budget (1997). Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. <https://www.govinfo.gov/content/pkg/FR-1997-10-30/pdf/97-28653.pdf>

<sup>53</sup> *Ibid.*

<sup>54</sup> The Initiative on Asian Americans and Pacific Islanders. The White House. Available at: <https://obamawhitehouse.archives.gov/administration/eop/aapi/data/data>

<sup>55</sup> U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language and Disability Status. Department of Health and Human Services. October 31, 2011. Available at: <https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status#IV>

<sup>56</sup> Z Codes Utilization among Medicare Fee-For-Service (FFS) Beneficiaries in 2017: Data Highlight. Centers for Medicare and Medicaid. Jan 2020. <https://www.cms.gov/files/document/cms-omh-january2020-zcode-data-highlightpdf.pdf>. Accessed 7 September 2021.

<sup>57</sup> Luque JS, Soulen G, Davila CB. et al. Access to health care for uninsured Latina immigrants in South Carolina. BMC Health Serv Res 18, 310 (2018). <https://doi.org/10.1186/s12913-018-3138-2>

information to determine treatment regimens. There is evidence that these algorithms can lead to bias in treatment decisions.<sup>58</sup>

Standardize demographic data to patient-centric elements: Robust collection of patient data should target the elements that matter most to patients. PhRMA suggests that the Caucus work with HHS and other health-related entities to utilize qualitative research techniques to evaluate and test which demographics and social determinants patients consider most important. Identifying the factors most important to diverse patients can facilitate progress towards a subset of standardized demographic and SDOH measures to be utilized across administrative data systems across communities. In addition, we recommend that CMS continue to test and pilot the level of granularity within each data element, similar to OMB's efforts to continue to refine race and ethnicity measurement.<sup>59</sup> Refinement of the granularity of data elements will help to ensure that pressing health disparities are not overlooked due to the aggregation of data elements.

Encourage collection of data at intersections of characteristics: Because populations may experience more than one source of disadvantage at a time, efforts to advance demographic data collection should also seek to collect information on social factors and their intersection with demographic information.<sup>60</sup> Intersectionality, a term coined by legal scholar Kimberlé Crenshaw, describes how intersecting systems of oppression (e.g., racism and sexism) have multiplicative impacts on an individual's life experiences.<sup>61</sup> Using a framework such as intersectionality to guide better data collection can reduce disparities in quality of care at intersections that influence health outcomes and patient experiences.

Promote interoperability: Enhancing health disparity data may also require consideration of incentives to encourage data collection and the infrastructure investment needed to facilitate interoperability. There is an opportunity for Federal programs and related entities, such as health care practices and systems, to promote data sharing to measure the uptake of underserved communities in Federal programs/activities and the impact of Federal programs and activities on eliminating health disparities. Electronic data sharing among plans could reduce burdens on providers and patients. For example, doctors spend about four hours per week on administrative tasks such as addressing drug formulary issues, prior authorization requests, and clarifying

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<sup>58</sup> Algorithmic Bias In Health Care: A Path Forward, " Health Affairs Blog, November 1, 2019.

<https://www.healthaffairs.org/doi/10.1377/hblog20191031.373615/full/>

<sup>59</sup> Proposals from the Federal Interagency Working Group for Revision of the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity. OMB. March 1, 2017.

<https://www.federalregister.gov/documents/2017/03/01/2017-03973/proposals-from-the-federal-interagency-working-group-for-revision-of-the-standards-for-maintaining>

<sup>60</sup> Nick G, Schloss K, Lekas HM, et al. A Social Determinants Perspective of the Intersection of Ageism, Racism, and Social Isolation During COVID-19. Behavioral Health News. Jan 1, 2021. Available at:

<https://behavioralhealthnews.org/a-social-determinants-perspective-of-the-intersection-of-ageism-racism-and-social-isolation-during-covid-19/>

<sup>61</sup> Crenshaw K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review, 43(6), 1241-1299. doi:10.2307/1229039

claims information.<sup>62</sup> Currently, fewer than 15 percent of administrative health care transactions are fully electronic, including eligibility verification, checking on claim status, prior authorization, and clinical information submitted with claims.<sup>63</sup>

Leverage existing data: We also recommend that the Caucus encourage opportunities to leverage existing data to better inform health care use and outcomes across important subpopulations, particularly as it relates to health disparities. These data could be conveyed in dashboard-style outputs. For example, CMS publicly reports select information on the Medicare and Medicaid populations using deidentified administrative claims data. CMS' Medicare Enrollment Dashboard includes information regarding the number of Medicare beneficiaries with hospital/medical coverage and prescription drug coverage<sup>64</sup> There also are dashboards on drug spending in Medicare Part D,<sup>65</sup> Medicare Part B,<sup>66</sup> and Medicaid<sup>67</sup> that could be enhanced to display disparities in outcomes. The Office of Minority Health also reports data on racial and geographic health disparities for select diseases and outcomes.<sup>68</sup> CMS' Office of Minority Health also has designed an interactive tool – the Mapping Medicare Disparities Tool – to identify areas of disparities between subgroups of Medicare beneficiaries, such as racial and ethnic groups, in health outcomes, utilization, and spending.<sup>69</sup> These tools could serve as a model for functional and comprehensive “disparity dashboards” that could be developed across agencies, with consistent definitions and outputs that reflect a broader range of diseases, outcomes, and utilization patterns, particularly for medicines.

Partner with community stakeholders to develop culturally sensitive data collection strategies. Direct engagement with community stakeholders (e.g., community-based organizations and community leaders) can help Federal agencies reach and collect data on underserved communities in a culturally sensitive manner. Community-based organizations and historically black colleges and universities (HBCUs) can assist with piloting and testing approaches to assess

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<sup>62</sup> Blanchfield et al. (2010). Saving Billions of Dollars- And Physicians' Time-By Streamlining Billing Practices. Health Affairs, 29(6), 1248-1254. Retrieved from <https://www.healthaffairs.org/doi/10.1377/hlthaff.2009.0075>

<sup>63</sup> CAQH, 2018 CAQH Index: A Report of Healthcare Industry Adoption of Electronic Business Transactions and Cost Savings, 2019. <https://www.caqh.org/sites/default/files/explorations/index/report/2018-index-report.pdf>

<sup>64</sup> Centers for Medicare & Medicaid Services: Medicare Enrollment Dashboard. Available at:

<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMSProgramStatistics/Dashboard>

<sup>65</sup> Centers for Medicare & Medicaid Services: Medicare Part D Drug Spending Dashboard and Data. Available at :

<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Information-on-Prescription-Drugs/MedicarePartD>

<sup>66</sup> Centers for Medicare & Medicaid Services: Medicare Part B Drug Spending Dashboard. Available at:

<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Information-on-Prescription-Drugs/MedicarePartB>

<sup>67</sup> Centers for Medicare & Medicaid Services: Medicaid Drug Spending Dashboard. Available at:

<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Information-on-Prescription-Drugs/Medicaid>

<sup>68</sup> Available at: [https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Geographic-Variation/GV\\_Dashboard](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Geographic-Variation/GV_Dashboard)

<sup>69</sup> Centers for Medicare & Medicaid Services Office of Minority Health: Mapping Medicare Disparities. Available at: <https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH-Mapping-Medicare-Disparities>

hurdles facing engagement and data collection on a regular basis. We recommend that the Caucus engage community leaders and organizations that have historically served predominately underserved groups, such as HBCUs, Tribal groups, and other entities, to implement culturally sensitive engagement strategies to collect data and evidence.

Research shows that reimbursing community health centers (CHC) for tasks including activities related to SDOH helps to increase their success in screening for SDOH.<sup>70</sup> Consistent with these findings, we recommend that Federal agencies consider providing financial and/or non-financial incentives for time spent on providing feedback and/or collecting data to advance the government's efforts to engage underserved communities.

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<sup>70</sup> Inga G, Bunce A, David, J, et al. Initiating and Implementing Social Determinants of Health Data Collection in Community Health Centers. *Population Health Management*. Feb. 2, 2021. Available at: <https://doi.org/10.1089/pop.2019.0205>