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September 21, 2021

The Honorable Cheri Bustos Congressional SDOH Caucus, Co-chair 1233 Longworth House Office Building United States House of Representatives Washington, DC 20515

The Honorable G.K. Butterfield Congressional SDOH Caucus, Co-chair 2080 Rayburn House Office Building United States House of Representatives Washington, DC 20515 The Honorable Tom Cole Congressional SDOH Caucus, Co-chair 2207 Rayburn House Office Building United States House of Representatives Washington, DC 20515

The Honorable Markwayne Mullin Congressional SDOH Caucus, Co-chair 2421 Rayburn House Office Building United States House of Representatives Washington, DC 20515

Dear Representatives Bustos, Cole, Butterfield, and Mullin:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing in response to the Congressional Social Determinants of Health (SDOH) Caucus' request for information (RFI).

The AMA recognizes racial and ethnic health inequities as a major public health problem in the U.S. and as a barrier to effective medical diagnosis and treatment. The elimination of racial and ethnic inequities in health care is an issue of highest priority for the AMA, and we advocate that health equity—defined as optimal health for all—be a goal for the U.S. health system. In order to address SDOH and health inequities, the AMA has created a new <u>Center for Health Equity</u> whose mission is to strengthen, amplify, and sustain the AMA's work to eliminate health inequities—improving health outcomes and closing disparity gaps—which are rooted in historical and contemporary injustices and discrimination.

According to Healthy People 2030, the "social determinants of health are conditions in the environment in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risk."¹ These social determinants include education, housing, wealth, income, and employment. We all experience conditions that socially determine our health or the SDOH. However, we do not all experience them equally.

The SDOH are impacted by larger and powerful systems that lead to discrimination, exploitation, marginalization, exclusion, and isolation. In this country, these historic and systemic realities are baked into structures, policies, and practices and produce, exacerbate, and perpetuate inequities among the SDOH, and, therefore, affect health itself. These larger, powerful systems of racism and gender oppression—also known as the root cause inequities—are upstream to the social determinants of health. They have shaped the social conditions in which people live, and they work to produce inequities across society in complex ways.

Below you will find the AMA's detailed responses to the questions contained in the RFI.

¹ <u>https://health.gov/healthypeople/objectives-and-data/social-determinants-health.</u>

EXPERIENCE WITH SDOH CHALLENGES

What specific SDOH challenges have you seen to have the most impact on health? What areas have changed most during the COVID-19 pandemic?

The AMA is strongly committed to improving health equity, health outcomes, SDOH, and decreasing health disparities. The COVID-19 pandemic, however, has created a concurrent public health and economic crisis that has exposed and exacerbated pervasive and severe access to care issues and social inequities. Not only has the pandemic disproportionally impacted minoritized and marginalized communities, but economic insecurity, housing insecurity, and food insecurity have disproportionately burdened communities of color and other underserved populations (e.g., rural areas) the hardest.

The COVID-19 pandemic has shown in stark reality the disparate impact that SDOH has on health outcomes in historically marginalized and minoritized communities. Lack of access to COVID-19 testing and testing sites primarily at the start of the pandemic in March 2020, as well as to high-quality hospitals and other health care facilities (especially long-term care facilities), and lack of health insurance or underinsurance, all contributed to disproportionately higher cases and deaths in communities of color. In some areas of the country, access improved by bringing testing to and establishing testing sites within underserved communities. Housing issues, including high-density and multi-generational families, employment in essential jobs, and food insecurity are also factors behind the disproportionate impact of COVID-19 on marginalized and minoritized communities. Vaccine hesitancy, due in part to historical and structural racism, as well as access issues, have been challenges in certain communities. Some of the reluctance to immunizations has improved in recent months through successful outreach by physicians and other health care professionals, local leaders, and businesses along with increased state and federal mandates.

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?

The AMA represents physicians across the nation and is widely regarded as the leading voice on Capitol Hill dedicated to promoting the art and science of medicine and the betterment of public health. Yet, for some physicians, the principal barrier or challenge to addressing SDOH is a lack of education and awareness on the impact of SDOH on patient outcomes. However, among physicians who are more cognizant of SDOH, barriers or challenges that are frequently reported include lack of time, resources, and tools to effectively address social needs of individual patients, in addition to SDOH within the communities in which they work.

To properly address SDOH, physicians and health systems must collect data on their patient population by screening for individual social needs, as well as understanding how these factors impact the community, at large. According to a study published in Journal of the American Medical Association, approximately 24 percent of hospitals and 16 percent of physician practices reported screening for food

insecurity, housing instability, utility needs, transportation needs, and interpersonal violence.² When researchers asked about barriers to screening, practices and hospitals primarily reported that the lack of screening was attributed to insufficient financial resources, time, and incentives.

Another study that examined physician attitudes regarding screening showed that while most health professionals supported social needs screening in clinical settings (84 percent), only a minority (41 percent) of clinicians expressed confidence in their ability to *address* social needs. In addition to reporting lack of time as a barrier, physicians also cite lack of resources to address any social needs identified (50 percent).³

Data sharing is another barrier to addressing SDOH. This includes data sharing between health systems and physicians, as well as between physicians and community-based organizations that assist individuals and localities with getting access to essential social services.

Health care systems and social services have traditionally operated in silos, which means systems are not currently designed to facilitate streamlined workflows. In a March 2021 report by the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services (HHS), titled "Social Determinants of Health Data Sharing at the Community Level", the following challenges were described as it pertains to data/information sharing: "…managing individuals' consent, lack of a standardized framework for collecting and storing information, standards for SDOH capture and sharing, and a platform to assist bi-directional exchange."⁴

A system-level gap that also serves as a main barrier to addressing SDOH is an insufficient financing or physician payment structure. Payments must be adequate in traditional fee-for-service systems, capitation, and value-based payment models to support physicians taking into account and addressing their patients' SDOH, for example, by compensating practices for identifying and coordinating provision of appropriate non-medical support services for their patients.

The AMA acknowledges that enjoyment of the highest attainable standard of health, in all its dimensions, is a basic human right, and that the provision of health care services as well as optimizing the SDOH is an ethical obligation of a civil society.

The AMA recognizes the 15 competencies of lifestyle medicine as defined by a blue-ribbon panel of experts convened in 2009 whose consensus statement was published in the Journal of the American Medical Association in 2010.⁵ The AMA continues to urge physicians to acquire and apply the 15 clinical competencies of lifestyle medicine, and offer evidence-based lifestyle interventions as the first and

 ² Fraze TK, Brewster AL, Lewis VA, Beidler LB, Murray GF, Colla CH. Prevalence of Screening for Food Insecurity, Housing Instability, Utility Needs, Transportation Needs, and Interpersonal Violence by US Physician Practices and Hospitals. JAMA Netw Open. 2019;2(9):e1911514. doi:10.1001/jamanetworkopen.2019.11514.
³ Schickedanz A, Hamity C, Rogers A, Sharp AL, Jackson A. Clinician Experiences and Attitudes Regarding Screening for Social Determinants of Health in a Large Integrated Health System. Med Care. 2019 Jun;57 Suppl 6 Suppl 2(Suppl 6 2):S197-S201. doi: 10.1097/MLR.0000000000001051. PMID: 31095061; PMCID: PMC6721844.
⁴ https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//199726/social-determinants-health-data-sharing.pdf.

⁵ Lianov L, Johnson M. Physician competencies for prescribing lifestyle medicine. JAMA. 2010 Jul 14;304(2):202-3. doi: 10.1001/jama.2010.903. PMID: 20628134.

primary mode of preventing and, when appropriate, treating chronic disease within clinical medicine. In addition, the AMA supports policies and mechanisms that incentivize and/or provide funding for the inclusion of lifestyle medicine education and social determinants of health in undergraduate, graduate and continuing medical education.

The AMA strongly supports efforts designed to integrate training in SDOH, cultural competence, and meeting the needs of underserved populations across the undergraduate medical school curriculum to assure that graduating medical students are well prepared to provide their patients safe, high quality and patient-centered care. The AMA also supports faculty development, particularly clinical faculty development, by medical schools to assure that they provide medical students' appropriate learning experiences to assure their cultural competence and knowledge of SDOH.

A clear gap exists in the availability of simple basic needs such as housing, safe drinking water, access to healthy foods and places to be physically active. As a result, the AMA, in collaboration with other health care and community-based organizations, is working to identify and eliminate the structural and social barriers that contribute to chronic diseases. The AMA continues to work to address SDOH through the promotion of diabetes prevention and lowering overall rates of hypertension, as well as our ongoing work to mitigate various other risk factors that can lead to improved health outcomes.

More specifically, the AMA has been working to establish clinical systems that identify patients at risk for diabetes along with referral processes to programs or interventions available in health care settings or the local community. Where we have seen the greatest success in addressing SDOH is in those health systems that use programs like Aunt Bertha's and One Degree, which are clearinghouses of programs and services that are integrated into clinical workflows, thus making it simple to find, refer, and track access to resources for patients.^{6,7} AMA remains committed to supporting and funding programs that establish more of these clearinghouses and infrastructure support programs so they can be embedded anywhere health care services are delivered.

Are there other federal policies that present challenges to addressing SDOH?

Federal policies and strategies that further strengthen efforts to address SDOH include (but are not limited to): Removing barriers to access to health insurance coverage and care (including expanding access to insurance subsidies to promote purchasing of health insurance coverage offered on the Affordable Care Act exchanges and the expansion of Medicaid); directing the Centers for Medicare & Medicaid Services (CMS) to incorporate SDOH data and provide support for addressing patients' SDOH in Medicare and Medicaid payment systems and alternative payment models; funding efforts to address SDOH along with identifying and overcoming existing barriers to implementing SDOH-related programs; and increasing funding to community-based organizations to strengthen infrastructure and capacity to coordinate and collaborate with patients and health care organizations.

Thankfully, Congress is working to assuage the impact of SDOH on patient care and **the AMA supports two crucial pieces of legislation that offer federal solutions to address these non-health care factors, specifically H.R. 2503, "the Social Determinants Accelerator Act of 2021," and S. 509, "the**

⁶ <u>https://company.auntbertha.com/</u>.

⁷ <u>https://www.1degree.org/</u>.

Leveraging Integrated Networks in Communities (LINC) to Address Social Needs Act."^{8,9} H.R. 2503 would provide \$25 million in planning grants to state, local, and tribal governments to design "social determinants accelerator plans" to improve the health and well-being of individuals, especially those participating in the Medicaid program. The legislation also stipulates that 20 percent of the funding be reserved for policy plans that assist rural populations. These plans could be targeted at a group of highneed Medicaid patients, such as homeless individuals, older workers with arthritis, nursing home patients, or mothers diagnosed with post-partum depression, as well as identify key outcomes to be achieved through improved coordination of health and non-health services and use of evidence-based treatments. The social determinants accelerator plans also would include provisions for linking data across programs measuring the impact of the new approach on the health of participants and the return-on-investment for taxpayers. An underlying goal of the accelerator plans is to develop ways to more effectively identify and utilize existing programs and authorities to address SDOH. To assist with this crucial task, the bill requires HHS to establish and convene the Social Determinants Accelerator Council, an inter-agency technical advisory council on SDOH. The technical assistance provided by the task force includes helping state, local, and tribal governments better leverage unknown or underutilized programs, along with developing rigorous program evaluation guidelines.

In addition, S. 509 would require the Secretary of HHS to award grants to states, on a competitive basis, to support the establishment of new or enhancement of existing community integration network infrastructure to connect health care providers to social services organizations in order to help patients overcome longstanding accessibility challenges related to various SDOH (e.g., food, housing, child development, job training, transportation, etc.). This federal effort to enhance communication between physicians and community social services infrastructure will undoubtedly improve patient outcomes.

AMA applauds the SDOH Caucus' leadership on H.R. 2503 and urges this bipartisan collection of federal lawmakers to continue pushing for enactment of both the Social Determinants Accelerator Act and the LINC to Address Social Needs Act into law during the 117th Congress.

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?

Existing Barriers to Medicare Beneficiaries Accessing Telehealth Undermines Efforts to Address SDOH

Technology can undoubtedly play a unique role in alleviating the negative impact of SDOH on patient outcomes. Yet, existing statutory limitations on access to telehealth services for Medicare beneficiaries, specifically the geographic and originating site restrictions, is a key federal policy that presents major challenges for physicians committed to addressing SDOH.

assn.org/letter/documentDownload?uri=%2Funstructured%2Fbinary%2Fletter%2FLETTERS%2F2021-6-4-AMA-Letter-to-House-re-Support-for-HR-2503-Social-Determinants-Accelerator-Act-v2.pdf. ⁹ https://searchlf.ama-

⁸ <u>https://searchlf.ama-</u>

assn.org/letter/documentDownload?uri=%2Funstructured%2Fbinary%2Fletter%2FLETTERS%2F2021-4-26-Letterto-Sullivan-and-Murphy-re-Leveraging-Integrated-Networks-in-Communities.pdf.

Under section 1834(m) of the Social Security Act (SSA), Medicare is prohibited from covering and paying for telehealth services delivered via two-way audio-visual technology unless care is provided at an eligible site in a rural area. This means that, in order to access telehealth services, patients must live in an eligible rural location, and must also travel to an eligible "originating site"—a qualified health care facility—to receive telehealth services, except in the few cases where Congress has authorized provision of telehealth services in the home of an individual. As a result, the 1834(m) restrictions bar the majority of Medicare beneficiaries from using widely available two-way audio-visual technologies to access covered telehealth services unless they live in a rural area, and with a few exceptions, even those in rural areas must travel to an eligible health care site.

Two-way audio-visual technology is the only communication modality on which Medicare places such a prohibition. Other communication technologies, including remote patient monitoring, do not meet the definition of a telehealth technology and services furnished via these technologies are not subject to the 1834(m) geographic and originating site restrictions and go through regular Medicare coverage and payment processes.

While these restrictions may have made sense given the limited technologies available when they were first instituted in the Balanced Budget Act of 1997, two-way audio-visual technology is now much more widely available and less expensive.

In response to the COVID-19 public health emergency (PHE), Congress passed the CARES Act, which, among other things, provided CMS the authority to waive the geographic origination requirement for the duration of the COVID-19 PHE, which CMS subsequently did. Following these policy actions, telehealth usage among Medicare beneficiaries has expanded greatly as patients could, for the first time, access telehealth services from wherever they are located, including their home, regardless of where they reside in the country. The AMA remains deeply grateful for these flexibilities, which have allowed Medicare patients across the country to receive care from their homes. With many physician offices closed, elective procedures postponed, personal protective equipment difficult to obtain, and an ongoing infectious disease pandemic that has forced patients to stay home for their safety, the ability to provide services directly to patients regardless of where they are located via telehealth has allowed many vital health care services to continue. In addition to facilitating continuity of care for patients experiencing potential COVID-19 symptoms and those who have been in close contact with people diagnosed with COVID-19 to determine if referrals for testing or treatment are indicated while minimizing risks to patients, practice staff, and others.

However, without further legislative action from Congress, Americans that have come to rely on telehealth services during the PHE will abruptly lose access to these services completely. Congress must act now to remove the origination and geographic restrictions on telehealth coverage for Medicare patients. Continued access to telehealth services beyond the PHE is critical for patient populations that have come to rely on its availability. That is why **the AMA supports S. 368/H.R. 1332, the "Telehealth Modernization Act of 2021," which would eliminate the 1834(m) statutory restrictions on originating site and geographic location, thereby ensuring Medicare coverage of telehealth services regardless of where the patient is located. It is crucially important, especially in the context of alleviating SDOH, that Medicare beneficiaries continue to be able to access telehealth services from their physicians without arbitrary restrictions throughout the COVID-19 public health emergency and beyond.**

Telehealth technologies allow physicians to increase continuity of care, extend access beyond normal clinic hours, and help overcome clinician shortages, especially in rural and other underserved populations. This ultimately helps health systems and physician practices focus more on chronic disease management, enhance patient wellness, improve efficiency, provide higher quality of care, and increase patient satisfaction. Telehealth has helped increase provider/patient communication, increase provider/patient trust, and access to real-time information related to a patient's social determinants of health, which can lead to better health outcomes and reduced care costs. The ability to gain greater access to chronic disease management services and better assess the impact of a patient's social determinants of health will undoubtedly contribute to improved treatment and health outcomes for historically marginalized and minoritized populations as well.

Telehealth services can also help patients avoid delaying care that can lead to expensive emergency department visits and hospitalizations. They also cut down on trips to the office that may be difficult or risky for patients with functional or mobility impairments, frail elderly who need a caregiver to accompany them, those who need to stay home to care for other family members, and patients who are immunocompromised or vulnerable to infection. Providing access to telehealth services creates greater safety and efficiencies for both patients and physicians, delivering value to the Medicare program.

Physician practices are ready to invest in the technology required to provide these services; however, it will be very difficult to provide the sustained financial commitment needed to incorporate delivery of telehealth services into their workflows if the coverage is only temporary. The removal of coverage and financial barriers has allowed the explosive growth in telehealth and certainty about future coverage is necessary for it to continue. It has allowed CMS to make more informed decisions about which services to cover, and, in fact, CMS has expanded coverage of telehealth services greatly during the PHE.

While CMS has expanded coverage of telehealth services during the PHE, only Congress can assure all Medicare beneficiaries can receive equal access to those services moving forward. Delaying action, such as extending the current 1834(m) waiver authority, will only increase the cost of making this necessary and overdue policy change.

Broadband Internet Access is a Social Determinant of Health

Lack of access to broadband and/or audio-visual capable devices is another major impediment to receiving high quality technology-enabled care for many Americans, including seniors in minoritized and marginalized communities where there were significant health disparities before COVID-19 that have become much worse during the pandemic. For example, according to the Federal Communications Commission, 628,000 tribal households lack access to standard broadband. Based on data from 14 participating states, the Centers for Disease Control and Prevention (CDC) reported that age-adjusted COVID-19–associated mortality among American Indian and Alaska Native persons was 1.8 times that among non-Hispanic Whites.¹⁰ Likewise, in an October 2020 article Government Technology reported that less than half the population in regions in Alabama with greater concentration of marginalized and minorized populations, have internet access, and two Alabama counties within this region have no internet access at all.¹¹ Marginalized urban communities have also been excluded from broadband service

¹⁰ <u>https://www.cdc.gov/mmwr/volumes/69/wr/mm6949a3.htm</u>.

¹¹ https://www.govtech.com/network/pandemic-worsens-internet-disparity-in-alabama-black-belt.html.

and need to rely on audio-only visits, because even when cities have broadband, many residents of these communities do not have access to it in their homes. A June 2020 report of the National Digital Inclusion Alliance describes data showing that the U.S. has more than three times as many urban as rural households living without home broadband of any kind.¹²

The AMA recognizes access to broadband internet as a SDOH and we believe it is vitally important to continue and broaden efforts to provide broadband internet access to all Americans. Ensuring access to broadband access and two-way audio-visual technologies would have a tremendous impact on alleviating challenges to access of digital health technology. In addition, initiatives to measure and strengthen digital literacy, with an emphasis on programs designed with and for historically marginalized and minoritized populations would help ensure that these communities can effectively use digital health tools once they have access to them. The AMA also supports efforts to design telehealth technology, including voice-activated technology, with and for those with difficulty accessing technology, such as older adults, individuals with vision impairment and individuals with disabilities.

IMPROVING ALIGNMENT

Where do you see opportunities for better coordination and alignment between community organizations, public health entities, and health organizations? What role can Congress play in facilitating such coordination so that effective social determinant interventions can be developed?

Opportunities exist for better coordination and alignment through increased funding and programmatic support for the SDOH program at the National Center for Chronic Disease Prevention and Health Promotion at the CDC, which the AMA supports. The Consolidated Appropriations Act, 2021 created a pilot program at the CDC based on "the Social Determinants Accelerator Act," H.R. 2503, which, as described above, the AMA also supports. We support building upon the initial investment in the CDC SDOH program to ensure that public health departments, academic institutions, and nonprofit organizations are properly supported to address the SDOH in their communities. The AMA also reiterates its previously stated support for S. 509, the "LINC to Address Social Needs Act." This important, bipartisan legislation provides critical network infrastructure support allowing for enhanced communication capabilities among physicians, social services, and community resources to help patients overcome longstanding challenges associated with SDOH.

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?

Empowering communities, and equally empowering individuals, is a key driver to addressing social determinants of health. Today's primary care physicians are expected to address the patient's existing medical condition while identifying any social barriers. Systems such as NowPow can be resources to linking individuals to programs and services.¹³

¹² https://www.digitalinclusion.org/digital-divide-and-systemic-racism/.

¹³ <u>https://nowpow.com/</u>

What are the key challenges related to the exchange of SDOH data between health care and public health organizations and social service organizations? How do these challenges vary across social needs (i.e., housing, food, etc.)? What tools, resources, or policies might assist in addressing such challenges?

The AMA appreciates Congress' recognition that certain individuals can benefit from social service agencies and community-based support programs (collectively, community-based organizations, or CBOs). Such programs often provide needed assistance to individuals who may not otherwise receive it. We also understand why access to a patient's protected health information (PHI), which may include SDOH data, can be used to improve an individual's health outcomes-particularly in the case of homelessness, limited access to health care services, or patients receiving multiple supports across a spectrum of services. Under current federal law, covered entities may share such information with noncovered entities for treatment purposes (including care coordination) without a patient's written authorization. Conversely, covered entities must generally obtain a patient's authorization before sharing PHI with non-health care providers (which are, by default, non-covered entities) for non-treatment purposes and, under current federal law, must limit such disclosures to the minimum necessary.¹⁴ Some, including the HHS Office for Civil Rights, have proposed modifications to the Health Insurance Portability and Accountability Act (HIPAA) to permit covered entities to disclose PHI to a non-health care provider for "health-related social services or other supportive services" without a patient's written authorization. However, this solution presents challenges and could lead to unintended consequences, as outlined below.

Just as it is difficult to truly define "health data," it is difficult to define "health-related social services or other supportive services." In other words, there are a wide range of CBOs who may seek to acquire and use PHI or other SDOH collected in the context of the physician-patient relationship, including community-run food pantries, halfway houses, crisis pregnancy centers, churches, schools, and day cares run out of an individual's home. While covered entities should not be restricted from providing PHI or SDOH data to any of these entities at a patient's request, we have significant concerns about requiring covered entities to share such information, particularly considering the information blocking regulations issued by the Office of the National Coordinator for Health Information Technology (ONC). The AMA believes that patients should have notice of, understanding around, and control over how their health care data is used and shared by covered entities with parties outside of their clinical care team, particularly for purposes beyond treatment. Yet, patients may not even be aware of what information the CBOs are requesting from their physician. Since the information blocking regulations compel a physician to disclose such information upon request by an entity acting on behalf of a patient, a patient may not have the opportunity to ask their physician not to share certain pieces of information—physicians will also be unable to utilize the "precondition not satisfied" exception of the information blocking regulations that would have allowed the physician to check with a patient before release of PHI. So, for example, a church might request information about an individual's medical appointments with the intent of assisting the patient with transportation to those appointments. But if the church receives information revealing the patient's same sex orientation or HIV-positive status, the patient may experience repercussions within his or her church community-including the loss of transportation assistance.

¹⁴ 45 Code of Federal Regulations (CFR) 164.506.

HL7's Gravity Project is a multi-stakeholder group that seeks to create and maintain a consensus-building community focused on expanding available SDOH core data for interoperability and accelerating standards-based information exchange by using Health Level 7 (HL7®) Fast Healthcare Interoperability Resources (FHIR®). It has issued Principles for Electronic Health Information Exchange and Data Stewardship that include a recommendation to ensure patients have personal control over their data: "Exchange and use of personal information should account for the diverse needs of all stakeholders, without erecting barriers or diminishing function or quality for those with differing abilities, languages, or cultural contexts...Each individual has the right to consent to, and challenge the collection, content, retention, use or disclosure of information relating to them, including the right to have the particular information corrected or omitted."¹⁵ These concepts align with the AMA's own Privacy Principles.¹⁶ We strongly encourage Congress to think critically around privacy protections for patients and the critical need to engage with the patient while discussing social risk factors, including how such data may be shared, for what purpose, and how the patient can amend such data.

Additionally, there are no federal restrictions around how CBOs may further use or disclose the PHI/SDOH data to other third parties, which is a significant risk to patient privacy of which patients may be unaware. They may think that if their physician is sending information to a CBO for "health-related" services, that the information will remain confidential—something for which there is no guarantee under current law. Yet, scores of companies use precisely this type of data in ways that can ultimately be harmful to individuals-data that can be easily obtained from CBOs if they do not have robust, equitable data governance practices and policies in place. By way of background and additional context, the Federal Trade Commission (FTC) released a *Report on Big Data* in 2016 to explore the potential of big data to both create opportunities for consumers and to exclude them from such opportunities.¹⁷ Unsurprisingly, the report found that big data offers vast possibilities for both help and harm. Specifically, it noted that big data creates the potential to target and exclude certain individuals and communities from educational, credit, health care, and employment opportunities. Unfortunately, the vast amounts of data that we produce – and which are aggregated, sliced, and diced by third parties – has facilitated the development of risk scores by a wide range of companies, including health insurers. These types of unchecked practices can amplify discrimination based on race, gender, sexual orientation, ability, age, financial status, and other group membership. For example, in March of 2019, the U.S. Department of Housing and Urban Development sued Facebook for "encouraging, enabling and causing housing discrimination" when it allows companies that use the platform to improperly shield who can see certain housing ads. HUD also alleged that "Facebook allowed advertisers certain tools on their advertising platform that could exclude people who were classified as 'non-American-born,' 'non-Christian' or 'interested in Hispanic culture," among other things." It also said advertisers could exclude people based on ZIP code, essentially "drawing a red line around those neighborhoods on a map" – a digital translation of the redlining policies that have oppressed marginalized populations across the United States historically, particularly throughout the 1900s.

¹⁵ https://confluence.hl7.org/display/GRAV/Gravity+Data+Principles.

¹⁶ Available at https://www.ama-assn.org/press-center/press-releases/ama-issues-new-principles-restore-trust-data-privacy.

¹⁷ <u>Big Data, a Tool for Inclusion or Exclusion?</u>, FTC, February 2016.

Congress' efforts to support exchange of SDOH information between health care organizations and CBOs must, therefore, contemplate how to prevent SDOH data from being used in harmful and discriminatory ways. Congress should, at a minimum, ensure that covered entities inform patients in a timely manner of (1) what CBO the patient's PHI/SDOH data is shared with; (2) what data was shared; and (3) the intended purpose of the disclosure. Ideally, patients would be provided an opportunity to object to such data being shared prior to its exchange. These safeguards should be distinct from HIPAA's accounting of disclosures policy that has yet to be implemented via regulation. Additionally, they should be implemented prior to (or concurrently with) any federal requirements to share PHI and SDOH with CBOs.

Congress should also consider that CBOs may not have electronic health records (EHRs) or any other type of digital data system with privacy/security safeguards to ensure the confidentiality and integrity of the individual's PHI. This potential unintended consequence is significant, particularly in small communities where word travels fast. CBOs may not have access controls or any meaningful way of ensuring that information about a patient is not accessible to anyone within the organization who does not need to know it. The vast majority of CBOs are under no legal obligation to ensure the privacy and security of PHI. Such assurances are very important for both physicians and patients and will be necessary to truly assist with improved health outcomes that could result from sharing of PHI and SDOH data. It is inappropriate to open the door to required PHI disclosure to entities that do not have the resources and infrastructure to protect the information. This does not mean that we should not work towards facilitating such information exchange. Rather, **prior to implementing legislative or regulatory changes, Congress and the appropriate federal agencies should prioritize additional financial, technical, and human resources to CBOs to help them manage the confidentiality of PHI and SDOH data.**

We also urge Congress to consider ways in which it can support the development and use of technology to manage patient privacy, which will be all the more important as SDOH data are increasingly collected and shared. For example, suppose a community food pantry (providing supportive services) requests PHI/SDOH data from a patient's oncologist. As an Actor under information blocking regulations, the oncologist would be required to disclose the requested food and medication allergy PHI stored in the physician's electronic health record (EHR), as well as information about the patient's options for fresh and healthy food in their community. However, the oncologist's EHR cannot send just the allergy and food-related SDOH data, so it instead sends a consolidated clinical document containing office notes, diagnostic results (including genetic tests), and problem list along with the patient's allergies. This lack of granular data management is common across EHR products. While ONC's regulations provide for exceptions allowing the physician to withhold information in some instances (e.g., when an EHR cannot segment data in compliance with state or federal law), identifying and documenting exceptions is complex and arduous, possibly resulting in an oversharing of information. Additionally, physicians are receiving inconsistent education and support from their EHR vendors on information blocking compliance. Clearly, a community food pantry should not have access to sensitive medical information. Yet, fear of not being HIPAA and information blocking compliant-coupled with limited EHR functionality and support—may promote risky data sharing practices impacting patient privacy. To address this, a health care organization could implement a security labeling service to tag data with special privacy considerations. Essentially, information is "tagged" to identify where the information originated, for what purposes it can be disclosed, and to whom. The need for such technology is increasingly critical as data continues to be generated outside of the clinical setting and would help to

solve burden associated with using and disclosing multiple types of sensitive data such as substance use disorder (SUD), HIV-status, genetic information, minors' health information, and reproductive health information. While we recognize that segmentation efforts do not seem to have been prioritized by developers, such technology currently exists, as recognized by ONC's Draft Report to Congress (Draft Report) on reducing regulatory and administrative burden relating to the use of health IT and EHRs:

[With respect to difficulty implementing Part 2 and integrating such information into EHRs,] HHS has recognized these implementation challenges and encourages the use of health IT to help clinicians appropriately share sensitive information while complying with legal requirements and respecting patient privacy preferences. For example, technical standards exist for electronically tagging health information to indicate privacy considerations, including legal requirements, within a patient record or summary of care document within the EHR, and SAMHSA supports ONC's Data Segmentation for Privacy initiative [DS4P] to support clinicians sharing of health information in accordance with patient choices. These tags on data elements, segments, or whole documents can then be used by automated access control solutions to prevent unauthorized access to patient data.¹⁸

ONC recommended in its Draft Report that HHS monitor, test, and support development of technical standards for data segmentation. We wholeheartedly agree with this recommendation, and strongly urge Congress to demonstrate its commitment to greater interoperability and privacy protections by prioritizing data segmentation development, testing, and policymaking. We note that while technology exists to segregate data and software can help to electronically manage patient consent (e.g., Consent2Share), we have heard from physicians and health systems that such segregation functionality is costly to implement, and that open-source consent management software can be prohibitively expensive to incorporate into a customized EHR. The Protecting Privacy to Promote Interoperability (PP2PI) workgroup, a consensusdriven group of cross-industry experts including patients, providers, health systems, heath IT developers, informaticists, and federal and state regulators, is working to advance technical standards and policy in this space.¹⁹ Congress can support these efforts by recognizing and prioritizing the pressing need for data segmentation to be made accessible and affordable to physicians. Such capabilities will enhance interoperability, strengthen the patient-physician relationship through a patient's increased confidence that a physician will not share SDOH data in a way that violates the patient's trust, and improve care coordination and patient outcomes resulting from a physician's ability to access sensitive information. Furthermore, such data segmentation capabilities would help to ease the burden stemming from physicians' compliance with state privacy laws. Congress should additionally support the efforts of organizations who adopt such data labeling technology to promote both access and privacy by creating safe harbors from HIPAA breach enforcement for organizations that adopt security labeling services.

¹⁸Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and EHRs, available at <u>https://www.healthit.gov/sites/default/files/page/2018-</u>

<u>11/Draft%20Strategy%20on%20Reducing%20Regulatory%20and%20Administrative%20Burden%20Relating.pdf</u>, p. 44.

¹⁹ <u>https://www.drummondgroup.com/pp2pi/</u>.

Finally, while SDOH data has the power to improve patient care and outcomes, the data are often highly sensitive, can lead to stigma, and can create or worsen inequities.²⁰ Additionally, such SDOH are not permanent; put differently, an individual's social risks and the SDOH that influence them may fluctuate dramatically over time, even in the short-term. Standardized terminologies and code sets can help to ensure consistency and will help to mitigate confusion and lack of clarity around how SDOH are defined and memorialized. The AMA has facilitated collaboration with other stakeholders to begin creating codes for SDOH. Current Procedural Terminology (CPT)[®] codes have been developed to describe services that address identified SDOH concerns, problems, or diagnoses. These SDOH concepts are integral to medical services and procedures used by clinicians. SDOH CPT codes have also been recognized by ONC and included in the United States Core Data for Interoperability (USCDI) version 2. The AMA is also a founding member of the aforementioned Gravity Project, which is responsible for²¹^[10]. The AMA's years of experience maintaining complex code sets has served as a critical resource to the Gravity Project. Since its inception, the AMA has played a significant role in the Project's governing bodies, and was critical in the development, standardization, and testing of the HL7[®] FHIR[®] SDOH implementation guide. We welcome the opportunity to discuss this work with Congress.

BEST PRACTICES AND OPPORTUNITIES

What are some programs/emergency flexibilities your organization leveraged to better address SDOH during the pandemic (i.e., emergency funding, emergency waivers, etc.)? Of the changes made, which would you like to see continued post-COVID?

During the COVID-19 PHE, CMS broke down many of the barriers that had previously made it difficult for physicians to provide telehealth services to patients insured by the Medicare program. It allowed patients all over the country to receive telehealth services, not just those in rural areas, and allowed them to get telehealth services in their homes instead of traveling to a medical facility. It added numerous services to the Medicare telehealth list, began paying for services at the same rates as in-office care instead of at reduced facility rates, allowed smart phones to be used, and provided coverage for audio-only services when patients cannot easily access audio-visual services. The AMA has participated in research documenting the growing use of digitally-enabled hybrid models of care, with a mix of in-person and virtual services.²² As discussed previously in this document, it is critical that the telehealth policies adopted during the PHE continue after the PHE ends.

In addition, the Drug Enforcement Administration (DEA) adopted special flexibilities for the treatment of patients with opioid use disorder (OUD) and for controlled substance prescriptions. During the PHE, physicians have been able to start and maintain patients on buprenorphine to treat OUD based on telehealth and audio-only visits. Physicians can also prescribe controlled substances based on telehealth visits. It is also extremely helpful for patients receiving methadone to be able to get take-home supplies. **Surveys in which AMA has participated have found that all of the flexibilities provided by the DEA**

²⁰ Laura M. Gottlieb, Hugh Alderwick, *Integrating Social and Medical Care: Could it Worsen Health and Increase Inequity?*, The Annals of Family Medicine Jan 2019, 17 (1) 77-81; DOI: 10.1370/afm.2339, available at https://www.annfammed.org/content/17/1/77.full.

²¹ <u>https://www.healthit.gov/isa/uscdi-data-class/procedures#uscdi-v2</u>.

²² <u>https://www.ama-assn.org/system/files/2021-05/ama-return-on-health-report-may-2021.pdf.</u>

have been extremely helpful to patients and physicians and we recommend maintaining them after the PHE.²³

In addition, the AMA recommends that the MDPP Expanded Model flexibilities be made permanent. Through the rulemaking process for the 2021 Medicare physician payment schedule, CMS adopted important flexibilities that are effective for the duration of the COVID-19 PHE and in future 1135 waiver emergencies that could cause a disruption to in-person Medicare Diabetes Prevention Program (MDPP) services. These MDPP policies will only apply in emergency situations, however, and not on an ongoing basis. MDPP services are being significantly underutilized. If the MDPP flexibilities that have been adopted for COVID-19 and future emergencies were instead continued as regular, ongoing MDPP policies, it would significantly strengthen the effectiveness of diabetes prevention services for Medicare patients with prediabetes. The AMA strongly urges Congress to pass H.R. 2807, "the PREVENT Diabetes Act."

To furnish virtual services during an emergency period, MDPP suppliers must already have preliminary or full CDC Diabetes Prevention Program recognition for in-person services. CMS continues to bar virtual-only suppliers that have achieved CDC recognition from furnishing MDPP services, even during the PHE. Under its current regulations, CMS will require MDPP providers to resume in-person services at the conclusion of the COVID-19 PHE. Against AMA urging, CMS has declined to allow virtual providers to participate in MDPP to the fullest extent either during or after the PHE. CMS regulations also prohibit patients from participating in their MDPP sessions virtually when offered by suppliers who provide both in-person and virtual services except during an emergency period. Many patients with prediabetes are unable to effectively participate in in-person MDPP sessions, often because they live far from any supplier location or because the sessions are not offered at times that are convenient for them. The MDPP should be modified to allow patients to obtain their session virtually at any time.

CMS regulations also impose a once-per-lifetime limit on patients obtaining MDPP services. During an emergency period, patients who continue their MDPP participation through virtual services will still be subject to the once-per-lifetime limit, but patients whose MDPP participation is interrupted by an emergency period will be able to restart MDPP services with the first core session after the emergency period ends. Other Medicare behavior modification programs such as tobacco cessation and obesity counseling do not have lifetime limits and there is no justification for a once-per-lifetime limit on MDPP services. This limit should be lifted for all patients, not just those who discontinue MDPP during a declared emergency.

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?

The AMA urges Congress to look to the North Carolina Department of Health and Human Services (DHHS) Healthy Opportunities Pilot as it is the nation's first comprehensive program to test evidence-

²³ https://searchlf.ama-

assn.org/letter/documentDownload?uri=%2Funstructured%2Fbinary%2Fletter%2FLETTERS%2F2020-11-20-Letter-to-McDermott-re-DEA-Telehealth-Flexibility.pdf.

based, non-medical interventions designed to reduce costs and improve the health of Medicaid beneficiaries.

TRANSFORMATIVE ACTIONS

Alternative payment models help to measure health care based on its outcomes, rather than its services. What opportunities exist to expand SDOH interventions in outcome-based alternative payment models and bundled payment models?

The AMA believes that CMS needs to provide adequate resources to help physician practices achieve better health outcomes for high-risk patient populations. For example, in the Medicare program, all patients with Medicare coverage do not have equal opportunities to achieve good health outcomes, so one-size-fits-all models are more likely to widen than reduce disparities. Payments within alternative payment models and performance measures should account for risk factors such as lack of access to food, housing, and/or transportation that affect patients' ability to adhere to treatment plans. Payment methodologies should also be designed to support and encourage practices to address patients' social needs, including by providing care management services and coordinating services across interprofessional teams.

Start-up funding should also be provided to participants in alternative payment models so they can invest in data analytic capabilities, care managers, training, and other practice changes needed to improve care delivery and facilitate successful participation. They should be designed with "on-ramps" that give participants time, as well as resources, to transform their practices before being expected to take on downside risk. Physician practices, particularly small and rural practices and those serving historically marginalized and minoritized patients, do not have financial reserves available to fund practice changes in advance of shared savings payments or to pay large penalties to CMS and other payers if their patients have greater SDOH and medical needs than can be supported by payment models.

Efforts need to be made to ensure that communities with greater SDOH needs are included in alternative payment models. For example, CMS primary care medical home models are now in their fourth iteration, but they still are not available in many states, including Alabama, Mississippi, and most states in the southeastern and southwestern U.S.

What are the main barriers to programs addressing SDOH and promoting in the communities you serve? What should Congress consider when developing legislative solutions to address these challenges?

The AMA strongly urges Congress to properly fund the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) at \$153 million for its Social Determinants of Health program – in line with President Biden's FY 2022 request.²⁴ We ask Congress to build upon their initial investment to ensure that public health departments, academic institutions, and nonprofit organizations are properly supported to address the SDOH in their communities.

²⁴ https://www.tfah.org/wp-content/uploads/2021/04/CDC_SDOHFunding_SignOn.pdf.

We appreciate the Congressional SDOH Caucus' leadership in working to address this critical issue. The pursuit of health equity is a pathway towards excellence in our health care system, one that ensures the valuing of human experience and rights. It is one that recognizes that we must do more as institutions to protect individuals and families. It will take all of us working in partnership—and the AMA is committed to doing so—to build and continue on a path forward to advance health equity. We look forward to continuing to work with the Caucus to advance these shared goals.

Sincerely,

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James L. Madara, MD