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Collecting Data to Ensure Equity in Payment Policy

BACKGROUND INFORMATION

The Center for Medicare & Medicaid Innovation (CMMI) was established as a key provision of the Affordable Care Act (ACA) to develop, test, and disseminate care and payment models to enhance health care quality and reduce spending. A decade later, with the combined learnings from more than 50 alternative payment models and the federal government's commitment to expand access to care and lower costs, CMMI is building on and expanding that foundation to catalyze a "stronger and more sustainable path forward" (Brooks-LaSure et al., 2021). To this end, the National Academy of Medicine (NAM) and CMMI have cooperated on a two-phase initiative to engage leading authorities in comprehensive consideration of key learnings and opportunities as CMMI lays the groundwork for a broader transformation of the nation's health and health care system. In Phase 1, a NAM-convened Expert Panel undertook a broad review of priority opportunities for CMMI to catalyze progress toward high-value, high-quality health and health care with enhanced effectiveness and efficiency in improving individual and population health. The Expert Panel issued a NAM-published Review outlining anchor commitments and action steps in support of CMMI's role as a catalyst for change (NAM, 2021).

In Phase 2, the Expert Panel transitioned to serve as a Steering Committee to guide the NAM in developing and convening a discussion series designed to provide operational and action-oriented steps to help address critical issues and challenges in two areas: *Multi-Payer Alignment on Value-Based Care* and *Collecting Data to Ensure Equity in Payment Policy.* This Discussion Proceedings will highlight priority areas and key themes that arose throughout the meeting, focused on collecting

MEETING SUMMARY

The Landscape of Data Collection to Support Equity Keynote

Cara James, Grantmakers In Health, defined health equity as the fair and just opportunity to be as healthy as possible as measured by the reduction and elimination of health disparities and their determinants that affect marginalized groups. Important types of data that the ACA requires to help address health equity include race, ethnicity, primary language, sex, and disability. However, the Secretary of the U.S. Department of Health & Human Services has the authority to add other measures, including socioeconomic status, sexual orientation, and gender identity. A report from the National Committee for Quality Assurance and Grantmakers in Health funded by the Commonwealth Fund found that data to understand and advance equity are severely lacking across U.S. government departments and agencies, except for data collected by Federally Qualified Health Centers (GIH and NCQA, 2021). Additionally, a 2016 National Academies report titled *Accounting for Social Risk Factors in Medicare Payments* found a lack of data on the social drivers of health, social relationships and context, and environmental context (NASEM, 2017). More concerning, the Centers for Medicare & Medicaid Services (CMS) reported that race and ethnicity data in Medicaid in 22 states are unusable (CMS, 2022). In James's view, data is also often missing at the local level for people of color, people who have disabilities, older people, and those living with mental and behavioral health issues.

James highlighted other considerations and challenges associated with collecting and using health equity data among CMS programs. First, data collection efforts could be more mindful of beneficiary and respondent burden in answering questions. Second, inconsistent data collection makes it hard to compare data, indicate and describe challenges, or even harmonize different aspects of data collected, such as different questions to beneficiaries about shelter and homelessness. Third, there is a lack of data collection standards, especially around race and ethnicity; James suggested a better data standard that is more congruent with the U.S.'s current population and a consistent execution strategy for collecting these data. Fourth, existing federal government data collection e

Disabilities

Barbara Kornblau, National Disability Mentoring Coalition, discussed how current data on disability status or the need for accommodations is not actively collected or considered by the broader health system, negatively impacting patient care experiences. For example, people with disabilities might require diﬀerent levels of support and treatment, such as physical accommodations for health screenings for people with diﬀerent kinds of disabilities. The lack of data and visibility, as well as optional ACA standards for accessible medical equipment, makes it challenging to provide high-quality care across the care continuum for people with disabilities. Kornblau noted that CMMI could benefit from having qualitative and quantitative data illustrating the experiences of people with disabilities within health and health care systems.

Aﬃrming Kornblau's remarks, *Michelle Doty Cabrera, County Behavioral Health Directors Association,* stressed the importance of expanding data collection for individuals with intellectual and developmental disabilities and taking an intersectional approach to understanding health outcomes in various subpopulations who are more likely to experience worse health and screen positive for a social drivers of health—for example, people of color from the LGBTQ+ community who also have disabilities. Cabrera added that death-related outcomes data could identify early mortality for individuals with disabilities or even Black, Indigenous, and People of Color (BIPOC) individuals by identifying discrimination and bias from providers within care settings.

Sexual Orientation and Gender Identity   hmor3 -1.2 Tpem DndivSutl

CMS's 2021 Measures Under Consideration list that also received conditional support through the 2021–2022 National Quality Forum Measure Applications Partnership (The White House, 2021). According to Perla, this heightened attention to the drivers of health present an unprecedented opportunity for CMMI and CMS to elevate this first instance of measures from a CMMI model toward inclusion in CMS quality and payment programs and models. Perla also noted that since the AHC model has drivers of health screening data and hierarchical condition category (HCC) risk scores on beneficiaries, CMMI could also continue its efforts to facilitate cross-referencing these data sets better understand the impact of social risk on cost (AAFP, 2022; Billioux et al., 2017). Incorporating drivers of health measures in CMMI programs and models could help CMMI demonstrate the possibility of efficiently and effectively scaling up drivers of health services and programs and signal their wide-reaching impacts on the health and well-being of beneficiaries.

In support of Perla's remarks, *Frederick Isasi, Families USA,* noted linking AHC social driver data with HCC data could create the case for investments and actions linking infrastructure, social drivers of health, federal spending, and health outcomes to restructure the health care system.

Open Discussion

Observations by Attendees

Opening remarks (CMMI's *Liz Fowler, Dora Hughes,* and *Kathryn Davidson*) affirmed President Biden's *Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government* (The White House, 2021). Fowler, Hughes, and Davidson identified the challenges of limited staffing, resources, and staff bandwidth as the overarching issue in collecting population-level data to address equity. CMMI is focused on assessing models for reach and their impact on underserved communities to inform their future approach. CMMI is launching successor models to Primary Care First and Comprehensive Primary Care Plus with considerations for data collection, geographic penetration, impact on underserved communities, specialty care, and implicit bias in eligibility criteria and payment algorithms. Additionally, they are studying data attribution methodology and assessing the impact of application criteria and eligibility as a barrier to reaching their goal of ensuring 100% of Medicare beneficiaries and the vast majority of Medicaid beneficiaries are in an accountable provider relationship by 2030. Finally, they are clarifying the legal basis upon which they could mandate race, ethnicity, and language data collection, as well as their ability to share these data with providers. The conversation moved toward suggestions for CMMI to overcome resource constraints and ensure meaningful stakeholder engagement, then toward the need to account for beneficiary and provider concerns, and finally, toward an urgent call to action for CMMI to begin moving rapidly on building the systems necessary to collect data that will ensure more equitable payment policies.

Reacting to CMMI's presentation of their ongoing activities, attendees noted a key concern was how CMMI could overcome resource constraints and encourage a broad, coordinated, multi-stakeholder effort on population-level data collection. These constraints prompted reflections on the need to act now and a call to action for the field with designated roles and responsibilities for all potential stakeholders. While waiting for more extensive efforts, such as new models and value-based payment innovations, CMMI could use already collected data on specific diseases such as diabetes and employ creative mechanisms such as secret shopper programs to evaluate providers.

To further increase stakeholder capacity and confidence, CMMI could also engage multi-stakeholder networks to aggregate complaints data, identify systemic problems, and use qualitative evaluations and analy-Þ ciaries.

Several considerations are prominent as CMMI discusses the next steps to advance equity. It is critical that CMMI capitalize on the current national discourse on equity in moving forward. President Biden's executive order on advancing racial equity and support for underserved communities and eorts by state and local entities to address justice and well-being for communities of color and the underserved present a launching pad for CMMI to add specificity to the call to action. Given the data, resources, partners, and political momentum available to leverage this current moment, there is substantial urgency to act as soon as possible to realize these goals.

This juncture also presents the opportunity for adopting a more intersectional approach to equity by collecting more granular and specific population health data that accounts for subpopulations and intersectionality across identities, circumstances, and lived experiences. At the point of care, it is critical that data allow for instant access and can inform the evaluation and treatment of care for beneficiaries. Data to ensure equity in payment policy also requires a more targeted and specific approach that examines how some populations suer even more significant disparities in the nation's health care system, especially if they experience one or more factors that could lead to greater disparities. These factors and characteristics include, but are not limited to, race and ethnicity, language, SOGI, geographic location and environmental context, disability status, behavioral and mental health issues, immigration and refugee status, and social drivers of health such as income, education, food access, health care access, and housing. Accounting for these intersecting and often overlapping identities can accurately capture the experiences and challenges faced by people in their daily lives and the impact on their health and well-being. These considerations can also inform eorts to reduce the cost barriers to accessing care and increase care utilization by populations disproportionately aected by a lack of health care aordability.

In conjunction with stakeholders, CMMI could also reexamine how value is defined. While cost containment is critical and an important part of CMMI's objectives, it is impossible to arrive at value without health and health care equity. CMMI and other stakeholders would benefit from examining the need for community investment as a strategy to arrive at a value-based care health system. CMMI could work synergistically with existing collaboratives, partnerships, and stakeholders engaged in equity data collection and use. Much work on equity data collection has been done, and many best and promising practices are available. To ensure these eorts can be implemented quickly, CMMI has an opportunity to learn from others and build o known successes, eorts, resources, and knowledge. The areas where CMMI could immediately learn from stakeholders include training providers and payers to collect race, ethnicity, language, and SOGI data to minimize patient concerns. These learnings could then be scaled to increase equity data collection capacity.

Additionally, CMMI has the potential and opportunity to work alongside its federal partners to implement equity data collection. During this discussion, many suggestions and comments about advancing equity in payment policy are also relevant for CMS, such as adding race/ethnicity data to the Medicare Part C and D application. For example, CMMI could elevate the first instance of measures from a CMMI model, such as the drivers of health measures from AHC, potentially becoming part of CMS quality and payment programs as an example of how model elements can scale across the government, drive alignment across federal programs, galvanize stakeholders, and send a powerful market signal to commercial/private payers.

Progress initiated by CMS on equity will greatly influence and impact CMMI and vice versa. CMMI and CMS could continue to work across the federal government, including the Oce of the National Coordinator for Health Information Technology and the Oce of Civil Rights, to ensure alignment in approaches to collecting, sharing, and using data to support equity. These organizations could help address a data-sharing landscape where sharing health data occurs unevenly across communities and in the volume, speed, and frequency with which health data is shared (Greene et al., 2021). These eorts would work on targeting populations disproportionately aected by institutional bias and discrimination across the aforementioned qualities and characteristics. Several priorities for action warrant emphasis.

1. **Signaling:** Reemphasize the key actions and steps that will be taken by CMMI and asked of payers, providers, and purchasers to prioritize equity, as well as indicate the short-, intermediate-, and long-term targets for collecting, sharing, and using equity data, including collecting reliable data that can be disaggregated, categorized, and targeted by subpopulations and communities.
2. **Mapping:** Develop, identify, and communicate the approaches, activities, and timelines used to meet targets through a comprehensive and actionable roadmap (e.g., providing culturally appropriate guid-

ance through training to empower health and health care stakeholders to clarify perceived and real barriers as well as motivate widespread data collection). The roadmap would ensure field alignment by communicating guidance, best practices, incentives, requirements, and core measures.

3. **Measuring:** Co-develop core data sets that measure performance on equity dimensions and display significance to field stakeholders, as well as patients, families, and communities. These measures, which should be both universal and targeted, could comprehensively account for, assess, and evaluate underserved populations' health, care, and outcomes. The measures should include considerations across race and ethnicity, language, SOGI, geographic and environmental context, disability status, behavioral and mental health issues, immigration and refugee status, and social drivers of health such as income, education, food access, health care access, and housing.

4. **Modeling:** Provide more substantial incentives to drive multi-stakeholder collaboration to collect equity data while providing learning tools, technical assistance, mechanisms, and funding for states, providers, and communities. States could use these resources to develop, coordinate, and lead innovations while proactively and continuously coordinating community stakeholders to inform these efforts. The resources could also help providers build and maintain the necessary capacity to collect data. Over time, the assistance would provide the collected data, documented community-based best practices and experiences, and align state, provider, and community stakeholders to test, implement, and craft community-level approaches and policies. These actions could address the needs of people disproportionately affected by institutional racism, multidimensional disparities through factors such as education and income, and the fee-for-service chassis.

5. **Partnering:** Develop a continuous and comprehensive multi-stakeholder community engagement approach that includes diverse and intersectional beneficiary perspectives as well as providers, payers, purchasers, and community-based organizations. These stakeholders would work to partner in collecting and sharing the needed data in an open, transparent, and timely manner. Through these collected data, stakeholders can better understand various perspectives, lived experiences, efforts, and unique needs at a more specific and granular scale. In addition to developing and refining approaches to advancing equity in payment policy, a multi-stakeholder partnership could help CMMI build broad-scale support and adopt their guidance and deliverables.

6. **Demonstrating:** Test innovative and creative strategies that incentivize and facilitate the adoption of health data collection in multiple contexts and diverse, intersectional populations. These innovations could, through evidence-based mechanisms, provide promising practices on measurably reducing bias and care malpractice, improving care outcomes, and driving investments into the community and social drivers of health. These learnings could then be incorporated into future CMMI efforts and disseminated across stakeholders collaborating with CMMI.

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