



# Patient Advocate Perspectives on Advancing Value-Based, Person-Centered Care

## The Role of Health Care Payment in Promoting Person-Centered Care

Health care in the United States has long struggled to deliver on key pillars of person-centered care: access, affordability, quality (including patient experience), and equity.<sup>1</sup> The reasons are manifold, but one consequential challenge is the way health care providers are paid to deliver care.

The traditional fee-for-service system (FFS), where health care providers are paid a separate fee for each service rendered regardless of the outcome, undervalues prevention, discourages care coordination, limits team-based care, and lacks accountability – all components necessary to promote quality and equity.

Value-based care (VBC), on the other hand, incentivizes better care and outcomes, and provides flexibility to support accessible, team-based, whole-person care for all communities, especially where most needed. When designed with input from individuals, caregivers, and advocates, VBC models have the potential to close gaps in quality of care and health outcomes.

While the future of Medicaid and Medicare is at great risk, with consequential implications for patients and families, VBC efforts will persist, and the needs of the people the health system is designed to serve must be and remain at the center.

## The Role of Individuals, Patients, and Consumers in Driving Payment Reform

Unfortunately, until recent efforts, individuals, caregivers, and advocates have had little to no role in shaping policy related to health care payment and delivery system reform. And the vast majority of payment reform efforts have made little to no progress in demonstrating a reduction in health inequities.<sup>2</sup> In an effort to engage more advocates and explore the impact of this evolving VBC movement, the National Partnership for Women & Families (NPWF) convened the Equity-Centered Payment Reform Learning Collaborative and hosted a five-part meeting series intended for shared learning and open dialogue among members and leading experts in the field.

In 2023, NPWF met with nearly 20 health equity and consumer advocacy organizations. We learned that many of these organizations have conflicting, higher-priority issues, leaving them with limited bandwidth and resources to dedicate to health care delivery and payment reform. Additionally, there is limited grant funding to support patient and consumer advocacy organizations in this field, hence the industry-dominated representation at multisector policy tables. Others remain concerned or skeptical of VBC, emphasizing the need for meaningful patient and consumer engagement to ensure appropriate guardrails exist to avoid widening inequities in new payment models.

In 2024, NPWF launched the Learning Collaborative (LC), bringing together experts on Medicare; Medicaid; dual eligibles; social drivers of health; racial, gender, and disability equity; patient and family engagement; and community health. Member organizations include the American Heart Association, the Center for Medicare Advocacy, the Medicare Rights Center, the National Health Care for the Homeless Council, and the National Urban League. Together, the collaborative surfaced common priorities to advance health equity and person-centered payment reform, including better capturing and stratifying data to identify inequities, understanding and using patient experience to improve quality of care, and engaging people with lived experience to help inform program design, implementation, and evaluation. Leaders on data, quality, and state Medicaid innovation shared insights and key policy developments on the future of equity-centered VBC – and the role patients and advocates can play in shaping that future.

## Learning Collaborative Key Takeaways

While participation in the LC does not necessarily constitute agreement with all of the report's content, the report benefited from members' input and expertise. Without attributing comments to any organization, what follows is a summary of the salient themes that emerged from the LC meeting series. NPWF wishes to express its sincere appreciation to all the LC participants.

### Key Takeaways

- Guardrails against exacerbating inequities or disincentivizing care
- Slow uptake among low-resourced providers
- Collection of patient self-reported data
- Use of patient-reported outcomes and experience data
- Persistent knowledge gap about payment reform opportunities
- Greater transparency of patient and community engagement



**Guardrails against exacerbating inequities or disincentivizing care.** Learning Collaborative participants raised concerns that health impacts caused by poor housing or other social drivers of health often undermine or offset the impact of primary care services. Participants emphasized the importance of [risk-adjusting](#) payments based on social risk factors to ensure providers treating patients with complex health and social needs are not penalized for outcomes beyond their control, and to also discourage providers from avoiding sicker and more costly patients (“lemon-dropping”).<sup>3</sup> However, if not done thoughtfully, adjusting payments based on inaccurate or incomplete data could also mask inequities and patients’ needs, leading to lower risk scores and payments.<sup>4</sup> Policies against fraudulently adjusting risk scores (“upcoding”), without creating undue administrative burdens for community-based providers, are equally important. Participants also underscored the need for capacity building funds and other investments for community-based providers to ensure effective participation and engagement in VBC models.

Participants highlighted the need for mechanisms that identify and address unintended consequences of payment models, including those identified via

consumer feedback on model design. For example, payments tied only to health improvements may not be appropriate for patients with chronic conditions, for whom the treatment goal is to maintain or slow decline of their condition(s).



**Slow uptake among low-resourced providers.** Participants emphasized that innovation in care delivery and payment is needed to drive equity, but the uptake is slower among low-resourced providers, including those serving Medicaid beneficiaries and working in primary care. The transition to value-based care in primary care for Medicaid beneficiaries and dual eligibles has its own difficulties. For example, many safety-net providers work under tight financial margins, driven in part by low Medicaid reimbursement and underinvestment in primary care. Therefore, they are often unable to assume any level of financial risk that some value-based care models require. They are also unable to cover the cost needed to transform care delivery, such as hiring more staff or upgrading health information technology. In addition, primary care providers are increasingly responsible for health-related factors outside their control with limited resources to address them. The CMS Innovation Center's (CMMI) recent strategy to strengthen the primary care infrastructure and launch more state-based models is promising.<sup>5</sup> And while VBC is not a solution to address workforce challenges, it can serve as a tool to provide greater resources and flexibility to primary care providers.



**Collection of patient self-reported data.** Participants noted it is difficult to assess the way models impact patients without having the right data and without stratification by race and ethnicity, disability, sexual orientation and gender identity, geography, etc. The gold standard for demographic and social needs data collection is self-reported.<sup>6</sup> However, several challenges must be addressed. For example, increased health-related social needs (HRSN) screening and reporting have caused concern for some patients wary of losing program eligibility and benefits.

Patient burden to respond to surveys, especially if requested frequently, is another concern for poor quality data.<sup>7</sup> Patients may be reluctant to share demographic information in fear of potential stigma or discrimination. Therefore, providers must also build trust with patients, so that they understand the collection of their self-reported demographic data is intended to identify service needs and health disparities.<sup>8</sup> CMS has identified promising practices and key insights from their Accountable Health Communities model.<sup>9</sup>

Participants also discussed the need for accountability and investments to ensure that referral loops are closed, and patients receive the supports they need, like

North Carolina's first statewide care coordination network, NCCARE360, that closes the loop on referrals to health and community resources.<sup>10</sup>

Finally, participants underscored the need for best practices for data infrastructure and data sharing for small practices and safety-net providers. Data infrastructure is foundational to closing gaps in care and outcomes, and many small and community-based providers do not have the resources or capacity to properly collect, store, share, and analyze data.



**Use of patient-reported outcomes and experience data.** Patient-reported outcome measures ([PROMs](#)) and patient-reported experience measures ([PREMs](#)) are necessary to advance person-centered care and equity. While these measures are not universally being used for quality improvement, CMS and other stakeholders are signaling greater interest in, and prioritization of, these measures in VBC.<sup>11</sup> There is an acute need for patient and caregiver input to the development of these measures to assess whether outcomes that matter to patients are improving, and whether patients are being treated with dignity and respect.



**Persistent knowledge gap about payment reform opportunities.** While the proliferation of CMS VBC models is accelerating the movement toward VBC, participants raised concern that the information gap between patients and caregivers and small and community-based providers persists. Patients and caregivers are unaware of VBC models, their inclusion in them, and the benefits they provide.<sup>12</sup> Participants worried that this causes confusion and limits patient engagement and their ability to take full advantage of benefits provided in VBC programs. Their lack of awareness also limits accountability and patients' ability to raise or address issues they may experience in new or existing models.

Participants discussed CMS's efforts to improve public communication about VBC and share stories of patients in [accountable care organizations](#).<sup>13</sup> However, information on their website does not provide beneficiaries specific information about whether and what models they may be included in. Public awareness about the CMS website is also often limited – raising the importance of partnering with patient advocates and community-based organizations for effective outreach and dissemination.

Additionally, participants surfaced that small and community-based providers in historically underserved communities may not be aware of new opportunities to participate in VBC models. Providers that do participate in these models may not fully understand the value of these reforms for their practice or their patients, particularly when there is often an increased administrative burden and required upfront costs.



**Greater transparency of patient and community engagement.** Participants underscored that new and existing models must do better to ensure they are meeting people’s needs, values, and preferences – and must be truly designed in a person-centered approach. Indeed, the term “person-centered care” is often misused, misunderstood, or sometimes even coopted in a profit-centered sector, defined by the industry perspective, without ever seeking input from people with lived experience.

While CMS has laudably increased its focus on strengthening partnerships with consumer and patient groups, it is unclear whether engagement is occurring early and regularly enough to influence the development of recent models. Consumer and patient advocates are also not always aware of the impact of models, which makes it difficult to hold CMS, providers, and other stakeholders accountable for patient access, quality, and equity.

## Looking Ahead

While the future of federal equity-focused efforts remains uncertain, there will continue to be opportunities to strengthen primary care, support behavioral health integration, improve rural health, and advance patient safety, experience, and outcomes through VBC. CMMI has launched several new models with core health equity components, which will require close monitoring.<sup>14</sup>

There has been significant bipartisan congressional activity on provider payment reform that may continue to build, including significant interest from the HHS Secretary, Robert F. Kennedy Jr.<sup>15</sup> The private sector may also continue to innovate on equity-related efforts like explicitly linking payment to equity.<sup>16</sup> Whatever happens, these recommendations should guide future work to advance value for patients and families:

- **Elevate and integrate lived experience in decision-making.** Valuing and meaningfully integrating lived experience in decision-making has incredible potential to influence the design of programs that can better address the significant challenges faced by everyone, but particularly historically marginalized groups. It can also be more responsive in meeting the needs of patients and caregivers.
- **Better capture and use real-time patient experience and outcome measures of what matters most to patients to drive continuous improvement initiatives.** When gathering patient experience and outcome data, patients and caregivers should know upfront why this information is being collected, what will be done with the information, and later, how the information is used to drive improvement.

- **Increase efforts to inform patients and caregivers about the benefits of and their inclusion in VBC models.** We could have a significant impact on patients and caregivers' health and experience by providing them with customized and understandable communications, in their primary language and in multiple formats, to ensure that they understand the benefits available to them in the VBC model they are assigned to. Further, this enables patient advocates to identify areas for improvement and to hold providers and payers accountable.
- **Continue making investments in data infrastructure and incentivizing privacy-preserving, self-reported data collection and robust analysis.** Incentivize providers to improve data collection and to report outcome measures stratified by factors such as geography, race and ethnicity, disability status, sexual orientation and gender identity, health-related social needs, and more. Data collection should be actionable and drive improvements in closing gaps. Providers should always protect individual privacy and confidentiality, while promoting the goal of integrated whole health. Patients and caregivers should also be included in decision-making on when, what, and how they are asked to report data to support reducing the burden of patient reporting.
- **Continue supporting safety-net and independent providers who serve a higher proportion of historically underserved communities** by implementing infrastructure investments and payment adjustments that reflect the actual costs of caring for those populations.
- **Expand the definition of success beyond short-term cost savings.** Evaluation and measurement limited to cost-effectiveness, cost-savings, or short-term return on investment will not adequately capture the return on upstream investments to improve long-term health.<sup>17</sup> Success must also align with patient priorities, and be defined by improving access, affordability, quality, and equity. It will also require providing greater investments to rural, small, and safety-net providers in underserved communities.

The Learning Collaborative series made clear that advocates for individuals, patients, and families see the promises and potential pitfalls of VBC to advance equity and person-centered care. As health care stakeholders continue to innovate, they should seek the perspectives and priorities of patients and caregivers, especially communities most affected, at all stages of policy development, including new laws, regulations, programs, and models. Tapping this critical resource has significant potential for VBC to yield better results and close the gap for patients, and make meaningful changes to the U.S. health care system.

## Endnotes

<sup>1</sup> The attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes. <https://www.cms.gov/pillar/health-equity>

<sup>2</sup> Sayed, B. A., Shaffer, N. C., Lewis, S. E., Cross-Barnet, C., Zucco, J., McNeely, J., & Woodman, S. Assessing equity to drive health care improvements: Learnings from the CMS Innovation Center. Retrieved 25 January 2025 from <https://www.cms.gov/priorities/innovation/data-and-reports/2023/assessing-equity-hc-improv-wp>

<sup>3</sup> Health Care Payment Learning & Action Network. Advancing health equity through APMs: Guidance on social risk adjustment. Retrieved 25 January 2025 from <https://hcp-lan.org/workproducts/APM-Guidance/Advancing-Health-Equity-Through-APMs-Social-Risk-Adjustment.pdf>

<sup>4</sup> Horstman, C., & Lewis, C. (2024, April 11). The basics of risk adjustment. The Commonwealth Fund. Retrieved 25 January 2025 from <https://www.commonwealthfund.org/publications/explainer/2024/apr/basics-risk-adjustment>

<sup>5</sup> De Marchis, E. H., Brown, E., Aceves, B., Loomba, V., Molina, M., Cartier, Y., ... Gottlieb, L. M. (2022, Summer). State of the science on social screening in healthcare settings. Social Interactions Research and Evaluation Network. Retrieved 25 January 2025 from <https://sirenetwork.ucsf.edu/sites/default/files/2022-06/final%20SCREEN%20State-of-Science-Report%5B55%5D.pdf>

<sup>6</sup> Centers for Medicare and Medicaid Services. (2022, November). The path forward: Improving data to advance health equity solutions. Retrieved 25 January 2025 from <https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf>

<sup>7</sup> Aiyegbusi, O. L., Cruz Rivera, S., Roydhouse, J., Kamudoni, P., Alder, Y., Anderson, N., ... Calvert, M. J. (2024, February 29). Recommendations to address

respondent burden associated with patient-reported outcome assessment. *Nature Medicine*, 30 650–659. [https://www.nature.com/articles/s41591-024-02827-9#:~:text=With%20regard%20to%20the%20completion,\)1%2C11%2C12](https://www.nature.com/articles/s41591-024-02827-9#:~:text=With%20regard%20to%20the%20completion,)1%2C11%2C12)

<sup>8</sup> De Marchis, E. H., Brown, E., Aceves, B., Loomba, V., Molina, M., Cartier, Y., ... Gottlieb, L. M. (2022, Summer). State of the science on social screening in healthcare settings. Social Interactions Research and Evaluation Network. Retrieved 25 January 2025 from <https://sirenetwork.ucsf.edu/sites/default/files/2022-06/final%20SCREEN%20State-of-Science-Report%5B55%5D.pdf>

<sup>9</sup> Centers for Medicare and Medicaid Services. (2023, December). A guide to using the accountable health communities health-related social needs screening tool: Promising practices and key insights. Retrieved 25 January 2025 from <https://www.cms.gov/priorities/innovation/media/document/ahcm-screeningtool-companion>

<sup>10</sup> Drake, C., Hinz, E. M., Granger, B. B., Granados, I., Rader, A., Pitcher, A., ... Spratt, S. (2024, March 18). Implementation of NCCARE360, a digital statewide closed-loop referral platform to improve health and social care coordination: Evidence from the North Carolina COVID-19 support services program. *North Carolina Medical Journal*, 85(2). <https://doi.org/10.18043/001c.94877>

<sup>11</sup> Bernheim, S. M., Rudolph, N., Quinton, J. K., Driessen, J., Rawal, P., & Fowler, E. (2024, April 17). Elevating quality, outcomes, and patient experience through value-based care: CMS Innovation Center's quality pathway. *New England Journal of Medicine Catalyst Innovations in Health Care Delivery*, 5(5). <https://doi.org/10.1056/CAT.24.0132>

<sup>12</sup> Health Care Transformation Task Force. (2024). Reimagining beneficiary engagement in accountable care models. Retrieved 25 January 2025 from [https://hcttf.org/wp-content/uploads/2024/07/Reimagining-Beneficiary-Engagement-in-Accountable-Care-Models\\_Final-1.pdf](https://hcttf.org/wp-content/uploads/2024/07/Reimagining-Beneficiary-Engagement-in-Accountable-Care-Models_Final-1.pdf)



<sup>13</sup> Centers for Medicare and Medicaid Services. Value-based care spotlight. Retrieved 25 January 2025 from <https://www.cms.gov/priorities/innovation-center/value-based-care-spotlight>

<sup>14</sup> The Accountable Care Organization Realizing Equity, Access, and Community Health (ACO REACH); ACO Primary Care Flex Model; Cell and Gene Therapy (CGT) Access Model; Guiding an Improved Dementia Experience (GUIDE) Model; Innovation in Behavioral Health (IBH) Model; Making Care Primary (MCP); States Advancing All-Payer Health Equity Approaches and Development (AHEAD) Model; Transforming Maternal Health (TMaH) Model

<sup>15</sup> Zhang, R. C. (2024, November 20). RFK Jr. is exploring a plan to upend Medicare's physician payments system. Stat. Retrieved 25 January 2025 from <https://www.statnews.com/2024/11/20/rfk-jr-ama-medicare-doctor-pay-ruc/>

<sup>16</sup> Blue Cross Blue Shield of Massachusetts. (2022, December 15). Blue Cross Blue Shield of Massachusetts signs groundbreaking value-based payment contracts incorporating equity measures. Retrieved 25 January 2025 from <https://newsroom.bluecrossma.com/2022-12-15-BLUE-CROSS-BLUE-SHIELD-OF-MASSACHUSETTS-SIGNS-GROUNDBREAKING-VALUE-BASED-PAYMENT-CONTRACTS-INCORPORATING-EQUITY-MEASURES>

<sup>17</sup> Health Care Payment Learning and Action Network. (2024, November). Value of health care redefined: Social return on investment. Retrieved 25 January 2025 from [https://hcp-lan.org/wp-content/uploads/2024/11/HCPLAN-Social-ROI-Publication\\_vFinal.pdf](https://hcp-lan.org/wp-content/uploads/2024/11/HCPLAN-Social-ROI-Publication_vFinal.pdf)

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