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BRIEF

Advancing Shared Decision Making among Patients of Color:

Lessons Learned from FAIR Health's Grant-Funded Initiative

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Summary

Although it shows promise for reducing unnecessary spending and healthcare costs,[1,2] as well as improving patient-provider communication,[3] shared decision making (SDM)—or the discussion between healthcare providers and patients and/or caregivers/care partners—has had limited adoption to date by healthcare providers. Tools such as decision aids are used to facilitate these discussions; however, healthcare costs are rarely included either in these tools or as part of SDM discussions.[4] Although SDM discussions have been shown to improve the quality of decisions and trust in physicians among patients of color,[5] patients of color may not have the SDM discussions with providers as often as their white counterparts.[6]

As part of its mission to advance transparency in healthcare costs and health insurance information, FAIR Health has undertaken consumer-focused, grant-funded initiatives to advance SDM among various patient populations. FAIR Health's first SDM project, funded by The New York Community Trust, focused on palliative care and led to the development and launch of a dedicated SDM feature on FAIR Health Consumer and three decision aids that combined clinical and cost information for three care scenarios for seriously ill patients: dialysis, ventilator and nutrition options. Building upon this project, FAIR Health undertook an initiative, funded by The Fan Fox and Leslie R. Samuels Foundation, that involved the development and 2021 launch of a provider-oriented educational platform website, FAIR Health Provider (fairhealthprovider.org).

In June 2021, NYHealth awarded FAIR Health—in collaboration with FAIR Health Academic Advisory Board member Chima Ndumele, PhD, Associate Professor of Public Health at Yale University—a grant to develop and launch decision aids to advance SDM among people of color in New York. With input from minority patients, providers and community health workers, as well as a comprehensive literature review, three conditions that disproportionately affect people of color were selected for the tools: uterine fibroids (separately, procedures and medications), slow-growing prostate cancer and type 2 diabetes. In May 2022, FAIR Health launched the four SDM tools, alongside educational content, resources and patient checklists on a dedicated SDM section of the FAIR Health Consumer website (fairhealthconsumer.org). To promote the tools, FAIR Health undertook a robust, culturally sensitive dissemination campaign, seeking to reach patients, healthcare providers, community healthcare workers and policy makers, among other stakeholders.

In this brief, FAIR Health presents salient findings and lessons learned throughout the project, An Initiative to Advance Shared Decision Making for Patients of Color. Key lessons learned include:

- **Utility and Usability of the New Decision Aids with Cost Information for SDM Discussions.** Qualitative feedback from patients and providers alike reflected the utility of the tools. Both groups noted that the tools were "very useful," with some stating that they will share the tools within their personal networks or with their patients. Feedback from surveys on FAIR Health Consumer indicated that 76 percent of participants found the cost information on the tools "useful" or "very useful"; 80 percent indicated that the tools rendered making a healthcare decision "easier" or "much easier." Prior insight from focus groups during the project's planning phase revealed that minority patients

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[1] David Arterburn et al., "Introducing Decision Aids at Group Health Was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs," *Health Affairs* 31, no. 9 (September 2012), https://doi.org/10.1377/hlthaff.2011.0686.
[2] Megan E Branda et al., "Shared Decision Making for Patients with Type 2 Diabetes: A Randomized Trial in Primary Care," *BMC Health Services Research* 13, no. 301 (August 2013), https://doi.org/10.1186/1472-6963-13-301.
[3] Stacey Dawn et al., "Decision Aids to Help People Who Are Facing Health Treatment or Screening Decisions," Cochrane, April 2017, https://www.cochrane.org/CD001431/COMMUN_decision-aids-help-people-who-are-facing-health-treatment-or-screening-decisions.
[4] J.S. Blumenthal-Barby et al., "The Neglected Topic: Presentation of Cost Information in Patient Decision Aids," *Medical Decision Making* 35, no. 4 (2015): 412-418. https://doi.org/10.1177/0272989X14564433.
[5] Aviva G. Nathan et al., "Use of Decision Aids with Minority Patients: A Systematic Review", *Journal of General Internal Medicine* 31 (2016): 663-676, https://doi.org/10.1007/s11606-016-3609-2.
[6] Monica E. Peek et al., "Race and Shared Decision-Making: Perspectives of African-Americans with Diabetes," *Social Science & Medicine* 71, no. 1 (2010): 1-9, https://doi.org/10.1016/j.socscimed.2010.03.014.

placed high importance on utilizing tools or resources from sources they trust: “information from credible messengers: peers, church pastors and other faith-based leaders, [and] nonprofit organization representatives if they have a particular rapport.”

- **Utility and Value of Ancillary Educational Content and Resources.** Ancillary materials, such as checklists and links to external resources, that complement decision aids may further aid SDM discussions between patients, particularly those from minority populations, and providers. Insights from consumers and healthcare providers pointed to satisfaction with the educational content and resources provided alongside the tools; focus group participants noted that the patient checklists were helpful. One focus group participant said that the checklists provided questions of which she had not thought. Printability and accessibility of the tools and resources were also highly valued. One patient stated, “One hundred percent of the toolkits and their checklists are helpful. One hundred percent.” This sentiment was echoed by other focus group participants. Based on website analytics, approximately 40 percent of all visitors to the SDM section of FAIR Health Consumer clicked on the checklists.

- **The Importance of Adaptability in a Multilevel Dissemination Campaign.** Prior insight from focus groups during the project’s planning phase revealed that minority patients placed high importance on utilizing tools or resources from sources they trust: “information from credible messengers: peers, church pastors and other faith-based leaders, [and] nonprofit organization representatives if they have a particular rapport.” As a result, FAIR Health undertook a grassroots dissemination campaign. Stakeholder outreach reached healthcare providers, state and federal departments of health, nursing organizations, nonprofit organizations, community health worker organizations and organizations that served or advocated for people of color. During the dissemination campaign, it was determined that reaching consumers and providers directly through Facebook ads would further promote awareness and use of the tools. The Facebook ad campaign led to a total of 1,056,657 impressions, 310,565 people reached and 14,753 click-throughs (accounting for 69 percent of visits to the tools) to the SDM section of the website. The tools on FAIR Health Consumer received over 21,300 unique visitors. Previous findings from FAIR Health’s SDM initiatives demonstrate that reaching both providers and consumers is critical to promoting awareness of the tools. On FAIR Health Provider, the SDM pages received an additional 4,900 visits since the launch of the tools for this initiative.

Background

Research suggests that decision support for certain conditions, such as breast and prostate cancers[7,8] and preference sensitive conditions,[9] may lead to better patient outcomes. Preference-sensitive conditions, or conditions where there is no clear clinical option and treatment is largely dependent on the patient’s values

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[7] Wendy L.T. Lam et al., “Reducing Treatment Decision Conflict Difficulties in Breast Cancer Surgery: A Randomized Controlled Trial,” *Journal of Clinical Oncology* 31, no. 23 (2013), https://doi.org/10.1200/JCO.2012.45.1856

[8] Stephen J. Lepore et al., “Informed Decision Making about Prostate Cancer Testing in Predominantly Immigrant Black Men: A Randomized Controlled Trial,” *Annals of Behavioral Medicine* 44, no. 3 (2012): 320-330, https://doi.org/10.1007/s12160-012-9392-3.

[9] David Veroff, Amy Marr and David E. Wennberg, “Enhanced Support for Shared Decision Making Reduced Costs of Care for Patients with Preference-Sensitive Conditions,” *Health Affairs* 32, no. 2, https://doi.org/10.1377/hlthaff.2011.0941

and preferences,[10] have had 5.3 percent lower medical costs, 9.9 percent fewer surgeries for related conditions and 12.5 percent fewer hospital admissions[11] in cases where SDM discussions have been held.

In the United States, patients often are responsible for a significant portion of healthcare costs, but do not always receive the care they prefer.[12] People of color, who experience health disparities and generally poorer healthcare outcomes, are especially affected by this. Studies show that patients of color, especially Blacks or African Americans, have reported experiencing discrimination and disrespect[13] and have expressed distrust in healthcare providers.[14]

Based on evaluative feedback from FAIR Health's prior SDM initiatives, combining cost information with clinical information in decision aid tools can enhance the utility of such tools. These findings were reported in two previous FAIR Health briefs, one from December 2020 and the other from February 2022. FAIR Health and Dr. Ndumele undertook a collaborative initiative, with generous funding from NYHealth, to develop new SDM tools for conditions that disproportionately affect people of color in New York State for inclusion on FAIR Health Consumer and FAIR Health Provider.

An Initiative to Advance Shared Decision Making in People of Color

This 18-month initiative featured four phases: Needs Assessment (three months), Development and Implementation (eight months), Dissemination (five months) and Evaluation (two months). Patients and providers of color were involved throughout the grant-funded project, including planning, development and evaluation phases.

In Phase I, FAIR Health, with guidance from Dr. Ndumele, undertook a needs assessment that included a comprehensive literature review and focus groups to inform the project deliverables and determine which conditions should be prioritized for the tools. Type 2 diabetes, slow-growing prostate cancer and uterine fibroids were selected as the conditions for the SDM tools; these conditions were confirmed during July 2021 focus group sessions with patients of color and providers who serve these communities. These initial focus group sessions were held with minority patients and providers to better understand the extent to which SDM was used and the patients' ability to navigate the healthcare system. Salient findings from these sessions were shared in this FAIR Health article. These insights informed the development and dissemination of the tools and ancillary content.

Following the needs assessment, FAIR Health undertook the development of the tools and content. FAIR Health licensed Option Grid™ decision aids from EBSCO; these tools offer clinical information for specific clinical scenarios. FAIR Health built the data pathways for the cost information utilizing FAIR Health's National Private Insurance Claims database, which now comprises 38 billion private healthcare claim records across all 50 states; Washington, DC; Puerto Rico; and the US Virgin Islands. FAIR Health also developed user

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[10] Arlene Bierman, Cathleen E. Morrow and Sheri Reder, "Shared Decision Making for Chronic Conditions and Long-Term Care Planning," presentation, Agency for Healthcare Research and Quality, July 26, 2016. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/education/curriculum-tools/shareddecisionmaking/webinars/sharewebinar716-slides.pdf.

[11] Veroff, Marr and Wennberg, "Enhanced Support for Shared Decision Making Reduced Costs of Care for Patients with Preference-Sensitive Conditions."

[12] Brian Zikmund-Fisher et al., "Deficits and Variations in Patients' Experience with Making 9 Common Medical Decisions: The DECISIONS Survey," *Medical Decision Making* 30, no. 5 (2010): 85-95, https://doi.org/10.1177/0272989X10380466.

[13] Meredith Grady and Tim Edgar, "Appendix D: Racial Disparities in Health Care: Highlights from Focus Group Findings," in *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, eds. Brian D. Smedley, Adrienne Y. Stith and Alan R. Nelson (Washington, DC: National Academies Press, 2003), 1-9.

[14] Elizabeth A. Jacobs et al., "Understanding African Americans' Views of the Trustworthiness of Physicians," *Journal of General Internal Medicine* 21, no. 6 (2006): 642-647, https://doi.org/10.1111/j.1525-1497.2006.00485.x.

interface designs for the new SDM section of the FAIR Health Consumer website and developed educational content to be presented alongside the tools, as well as patient and provider checklists with salient questions to ask before, during and after office visits. Links to external resources for patients were also posted to the site.

In May 2022, FAIR Health launched the new tools and content and began implementation of a robust, multilevel dissemination and grassroots outreach campaign. This campaign sought to target a wide variety of stakeholders, including community health organizations, organizations that serve and support people of color, nursing organizations, providers, hospital systems, patients and departments of health, among others. Culturally sensitive promotional materials were shared widely through social media, the press and a grassroots dissemination campaign. Following the grassroots campaign, it was determined that implementing social media ads would reach a wider range of patients and providers.

FAIR Health's evaluation of the initiative involved the collection of qualitative (through focus group sessions) and quantitative (through surveys and analytics) data. To gather quantitative data, FAIR Health posted an SDM survey with the tools during launch. Qualitative data and feedback were gathered from a series of focus groups with patients, providers and caregivers. Findings are discussed below.

Project Learnings

This initiative offered a unique opportunity to better understand how SDM tools combining clinical and cost information could empower consumers from minority populations to undertake SDM discussions with their providers. The initiative also offered the opportunity to learn how diverse patient populations navigate the healthcare system and the attendant challenges that they may face, as well as the opportunity to better understand barriers to SDM adoption among providers. Throughout the evaluative phase, FAIR Health sought to determine acceptability and perceived utility of the tools, educational content, checklists and resources. From the May launch through the end of the grant period in November, the SDM section of FAIR Health consumer received over 21,300 unique visits.

Utility and Usability of the New Decision Aids with Cost Information for SDM Discussions

Qualitative data indicated that patients and providers found the tools easy to use, and the SDM section of FAIR Health Consumer easy to navigate. One patient stated: "I was intrigued with the fact that it actually showed the patients the different types of opportunities they have….Because most patients, they kind of are in the dark about what they're getting themselves into.…I just think the fear factor's going to be gone now, by my point of view."

One provider echoed feedback from the initial round of focus groups:

> "When one looks at, historically, our healthcare system…shared decision making hasn't been part of it. But there's also been atrocities towards historically marginalized populations when engaging with the healthcare system. It brings a lot of distrust….When I was going through this shared decision-making tool, I have to say on my part, it was my first time ever seeing the costs laid out in such a detailed manner. I was astounded. And I said, 'Wow, this is excellent.' And I think it provides an opportunity for patients to really engage in the cost, see for themselves what the cost is, and then make an informed decision from there."

A third patient stated that if she'd had the tool for type 2 diabetes, she would have been able to advocate for herself when struggling with diabetes: "And I saw on your tools, it said, 'Do you want slow-acting? Do you want long-lasting?' See, if I had known that was out there, I could have saved myself all this headache from the bad medicine."

Quantitative data also supported patient satisfaction with the tools, with 80 percent of survey respondents overall indicating that they felt the tools made reaching a decision “easier” or “much easier”; 76 percent of respondents overall indicated that the cost information was “helpful” or “very helpful.” The tool with the highest amount of utilization was the type 2 diabetes treatment options tool, with 50 percent of users having utilized it. Seven out of 10 survey respondents indicated they understood the condition relating to the tool(s) they looked at “more” or “much more.” Eight out of 10 respondents said they would recommend the tools to others.

Utility and Value of Ancillary Educational Content and Resources

Qualitative feedback from focus group participants indicated that the educational content and resources were helpful. One patient stated: “I thought the checklists were pretty thorough, and I feel like they're helpful. And I liked that you could download the printable version of it, which I thought was good to have.” Another patient remarked: “I really liked the shared decision-making checklist. I thought it was very helpful. It gave you a lot of exploratory questions to prepare, like before, during and after the appointment, that wouldn’t have really crossed my mind.” A third added: “I think 100 percent of the toolkits and their checklists are helpful. One hundred percent, and you can be sure when you do that. This is good. You have the satisfaction, they make sure that you select the best one provided, and the best one treatment.”

Focus group participants also offered positive feedback on the resources. According to one such participant, an outreach provider: “I appreciate this information. And I’m one to share. And I’m wanting to do my homework. So I like to do my own little investigation.”

Quantitative data supported the qualitative feedback received. When asked which aspects of the SDM section of this website they found helpful, 26 percent of respondents said the tools, 57 percent said the checklists and toolkits and 55 percent said the resources; these findings may suggest consumers found the decision aids useful in tandem with the accompanying educational content and resources.

The Importance of Adaptability in a Multilevel Dissemination Campaign

FAIR Health has learned from previous campaigns that change is sometimes necessary mid-flight. FAIR Health implemented a grassroots dissemination campaign, influenced by feedback from the initial focus groups about trusting local organizations and individuals. Outreach to over 75 different organizations and individuals was performed, but in many cases there were challenges to the uptake of the tools in institutional settings, given their other pressing priorities. Having experience with promoting the usage of consumer tools through Facebook ads, FAIR Health added Facebook ads to the dissemination campaign.

Facebook ads targeted consumers and providers. In total, the Facebook ads reached 310,565 people and generated 1,056,657 impressions; the ads led to 14,753 link clicks to the SDM section of FAIR Health Consumer. The addition of these ads allowed the tools to reach new pools of potential users of the SDM tools and resources.

Conclusion

SDM tools continue to show promise for increasing patient empowerment and decision making, particularly when information about healthcare costs is also offered. FAIR Health’s initiative, generously funded by NYHealth, allowed FAIR Health to pilot SDM tools for minority populations in New York State to determine how such tools could equip these communities to better navigate the healthcare system and make the best healthcare decisions for themselves and their families. Program findings indicate that there remains an appetite for tools such as these, especially those with cost information. Findings also indicate that patients and providers alike thought that the tools were acceptable and useful; combined with ongoing dissemination, this may encourage more SDM discussions between patients—particularly those in minority communities—

and their providers and may continue to further SDM and consumer knowledge of condition-specific treatment options and related costs.

Project findings indicated the importance of maintaining a flexible dissemination campaign to reach those who stand to benefit most.

Future SDM initiatives potentially undertaken by FAIR Health could explore how tools that facilitate SDM discussions may increase health literacy in other vulnerable populations or explore other conditions for new tools for minority populations. Moreover, the addition of cost information to SDM has made providers aware of medical costs for patients; equipping consumers with this information can empower them and improve their overall navigation of the healthcare system.

FAIR Health thanks Dr. Chima Ndumele of Yale University for his guidance during this collaboration. FAIR Health also thanks the New York Health Foundation for its generous support of this initiative.

About FAIR Health

FAIR Health is a national, independent nonprofit organization dedicated to bringing transparency to healthcare costs and health insurance information through data products, consumer resources and health systems research support. FAIR Health qualifies as a public charity under section 501(c)(3) of the federal tax code. FAIR Health possesses the nation's largest collection of private healthcare claims data, which includes over 38 billion claim records and is growing at a rate of over 2 billion claim records a year. FAIR Health licenses its privately billed data and data products—including benchmark modules, data visualizations, custom analytics and market indices—to commercial insurers and self-insurers, employers, providers, hospitals and healthcare systems, government agencies, researchers and others. Certified by the Centers for Medicare & Medicaid Services (CMS) as a national Qualified Entity, FAIR Health also receives data representing the experience of all individuals enrolled in traditional Medicare Parts A, B and D; FAIR Health includes among the private claims data in its database, data on Medicare Advantage enrollees. FAIR Health can produce insightful analytic reports and data products based on combined Medicare and commercial claims data for government, providers, payors and other authorized users. FAIR Health's free, award-winning, national consumer websites are fairhealthconsumer.org and fairhealthconsumidor.org.

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