

BRIEF

# Advancing Shared Decision Making among Older Adults with Serious Health Conditions

Lessons from FAIR Health's  
Grant-Funded Initiative

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# Summary

Adults aged 65 and older make up a rapidly growing segment of the US population. Despite advances in healthcare and healthcare delivery, adults aged 65 and older face numerous challenges when navigating the healthcare system. Although older adults shoulder a significant portion of healthcare costs, they do not always get the care that they prefer.<sup>1</sup> Furthermore, while most older adults prefer to know the costs of their care, they seldom discuss costs with their healthcare providers.<sup>2,3</sup> Likewise, family caregivers and care partners, who assume a wide range of responsibilities related to care coordination and direct care, may possess limited resources and training to help them navigate the healthcare system and manage costs on behalf of their care receiver.<sup>4</sup>

Shared decision making shows promise for engaging older patients and their caregivers/care partners in healthcare decisions and reducing unnecessary spending<sup>5,6</sup> and healthcare costs.<sup>7,8</sup> Shared decision making involves communication between patients (and if applicable, their caregivers/care partners) and providers to decide on tests, treatment and care based on clinical evidence, balancing risks and outcomes with patient and caregiver/care partner preferences and values.<sup>9</sup>

In keeping with its mission to advance cost transparency, FAIR Health has led grant-funded initiatives that have resulted in the addition of shared decision-making tools for various health conditions, educational content and resources to its free, national consumer website [fairhealthconsumer.org](https://www.fairhealthconsumer.org) (FAIR Health Consumer). The tools combine clinical information from EBSCO's OptionGrid™ decision aids and cost data from FAIR Health's private healthcare claims database comprising over 40 billion claim records from 2002 to the present. In June 2021, The John A. Hartford Foundation (JAHF) awarded FAIR Health a grant to develop and launch an initiative to advance shared decision making among older adults with serious health conditions and family caregivers and care partners. The project, "A National Initiative to Advance Cost Information in Shared Decision Making for Serious Health Conditions," built on [previous shared decision-making initiatives](#) targeting seriously ill patients, minority communities and healthcare providers.

# Summary

In September 2022, FAIR Health launched the tools alongside a rich array of educational content and resources relevant to these conditions on a [dedicated section](#) of FAIR Health Consumer. FAIR Health gauged the perceived value and utility of the tools using a survey and focus group discussions with older patients, family caregivers, care partners and providers.

In this brief, FAIR Health presents salient insights from the project that can inform future initiatives and policies that seek to improve healthcare for older adults. Among the key learnings:

- **Shared decision-making tools and resources were seen as helpful in advancing shared decision making.** Feedback from older patients, family caregivers, care partners and providers pointed to the utility of the tools, content and resources in navigating the healthcare system, preparing for clinical visits and providing a fuller picture of treatment options and costs associated with care.
- **Shared decision making is perceived as a vehicle for patient empowerment.** Providers, patients, family caregivers and care partners alike believed that the tools, content and resources empowered individuals to become more active participants in their health and healthcare decision making.
- **Patients, family caregivers and care partners voiced their frustrations with healthcare costs, billing and a lack of transparency in the healthcare system.** During discussions with providers, patients, family caregivers and care partners, the aforementioned factors were cited as barriers to accessing care and relevant services.
- **Checklists and links to external resources were popular among older adults, family caregivers and care partners.** When asked which features were most helpful for their decision making, most older adults, family caregivers and care partners chose resource links to external organizations and websites and FH<sup>®</sup> Healthcare Toolkit checklists and articles.
- **Barriers to shared decision making exist at the point of care and at home.** In addition to a lack of transparency in costs and information related to clinical conditions, other barriers noted by participants included lack of technology access, low health literacy and time constraints during clinical appointments.

# Background

Despite concerted efforts to improve healthcare for aging adults, adults aged 65 and older continue to face numerous challenges in accessing high-quality care. Furthermore, recent studies have shown that older adults and family caregivers/care partners shoulder a significant portion of healthcare costs, though they do not always get the care that they prefer.<sup>10</sup>

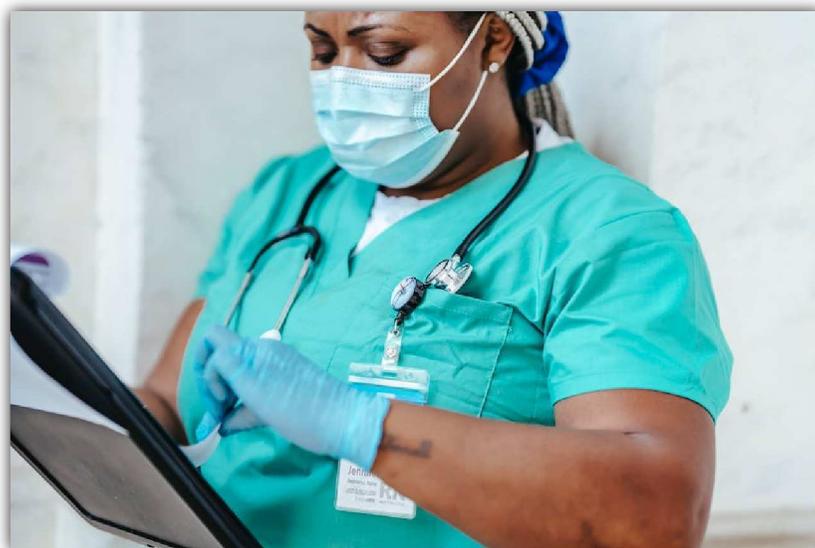
For older adults, especially those with multiple comorbidities, accessing high-quality care is a challenging process due to a lack of coordination between healthcare providers, conflicting recommendations from different healthcare professionals,<sup>11</sup> inadequate guidance and the inability to understand insurance plans,<sup>12</sup> often leading to fragmented care and higher treatment costs. Similarly, family caregivers/care partners, who assume a wide range of responsibilities related to care coordination and direct care, are offered few resources and little training to help them manage their care receivers' care and the costs associated with it.<sup>13</sup>



# Background

Shared decision making involves communication between patients (and if applicable, their caregivers/care partners) and providers to decide on tests, treatment and care based on clinical evidence, balancing risks and outcomes with patient and caregiver/care partner preferences and values.<sup>14</sup> Shared decision making shows promise for engaging older patients and their caregivers/care partners in healthcare decisions and reducing unnecessary spending<sup>15,16</sup> and healthcare costs.<sup>17,18</sup> Furthermore, various studies have suggested an association between shared decision making and increased patient satisfaction,<sup>19</sup> decreased symptom burden,<sup>20</sup> increased knowledge, and improved clinical interaction and communication between patients and their healthcare providers and clinicians.<sup>21</sup> This is especially important considering the growing issue of “financial toxicity”—the financial, emotional and mental burden patients experience with medical costs that can lead to diminished access to care and a reduced quality of life.<sup>22,23</sup> However, despite a growing appetite for shared decision-making tools and resources—especially those that incorporate cost conversations—decision aids rarely include cost information.

FAIR Health has dedicated its efforts and resources to addressing this gap and advancing shared decision making among vulnerable populations. Previous shared decision-making initiatives implemented by FAIR Health have demonstrated the value and utility of shared decision-making tools that combine clinical and cost information associated with different treatment options for various health conditions.



# A National Initiative to Advance Cost Information in Shared Decision Making for Serious Health Conditions

The 18-month initiative comprised four phases: needs assessment (Phase 1), development (Phase 2), evaluation (Phase 3) and dissemination (Phase 4). During the needs assessment, FAIR Health finalized the selection of conditions for which the tools would be developed based on a review of the literature on acute and chronic illnesses prevalent among older adults and in collaboration with leading experts in aging at JAHF and a multi-stakeholder Project Advisory Board.

In an effort to better understand the perspectives and needs of adults aged 65 and older, family caregivers and care partners when making healthcare decisions and navigating the healthcare system, FAIR Health also conducted two national surveys that assessed the perspectives of older adults, family caregivers and care partners on healthcare decision making (including shared decision making), the impact of healthcare costs on healthcare decisions, and challenges in navigating the healthcare system. Likewise, the literature review identified common acute and chronic illnesses among older adults and how these conditions impact the quality of life of older adults, their caregivers/care partners and families. The literature review also helped inform key research questions that shaped each project phase. Salient findings from the literature review and surveys were shared in a FAIR Health report, [\*Healthcare Navigation and Decision Making: Perspectives of Adults Aged 65 and Older and Family Caregivers\*](#). Insights gleaned from the needs assessment phase contributed to the finalized selection of conditions, which included: (1) for the shared decision-making tools: early-stage breast cancer, fast-growing prostate cancer, hip osteoarthritis, hip replacement and spinal stenosis; and (2) for the FH® Total Treatment Cost scenarios: Alzheimer’s disease/dementia, heart failure and major depression. The needs assessment findings also informed the development of contextualizing educational content and resources.

The selection of the conditions was based on a review of the literature on common acute and chronic illnesses for older adults, an analysis of FAIR Health data in relation to the EBSCO Option Grid™ decision aid offerings (to determine the most feasible clinical topics for developing shared decision-making tools that combine both clinical and cost information) and discussion with JAHF and the Project Advisory Board.

# A National Initiative to Advance Cost Information in Shared Decision Making for Serious Health Conditions

The needs assessment during **Phase 1** also helped inform key research questions outlined in our proposal. Through a literature review and analyses of the national survey responses and qualitative feedback from focus groups, the assessment further established the importance of providing cost information through consumer-friendly tools and resources for consumers. It also underscored that healthcare providers, including nurses, are a critical part of advancing shared decision making.

During the development phase, FAIR Health developed the tools for the aforementioned conditions, which encompassed building data pathways for the cost information provided by FAIR Health's National Private Insurance Claims (FH NPIC®) database and developing user interface designs for a new section dedicated to older adults, family caregivers and care partners on the FAIR Health consumer website. In parallel, we developed educational content on financial health literacy, patient- and caregiver-oriented checklists with suggested questions to ask providers and plans, and links to external resources relevant to the conditions.

In September 2022, FAIR Health launched the new tools, content and resources on a new **Older Adults section** of [fairhealthconsumer.org](https://www.fairhealthconsumer.org) (FAIR Health Consumer) and on [fairhealthprovider.org](https://www.fairhealthprovider.org) (FAIR Health Provider), which offers the tools and educational content geared for clinicians. The launch kicked off a robust dissemination campaign, which promoted the tools through a media campaign, social media campaign and outreach and targeted a wide range of healthcare stakeholders (e.g., consumers, healthcare providers, family caregivers, care partners, policy makers, researchers and community-based organizations) primarily in four geographic markets: New York, NY; Atlanta, GA; Los Angeles, CA; and Chicago IL, and their surrounding areas.

FAIR Health utilized a mixed methods approach to gauge the acceptability of the tools, content and resources. Quantitative data sources included Google Analytics, survey data, press coverage circulation and social media reach. Qualitative data sources included feedback from focus group sessions with providers, patients, family caregivers and care partners.

# Program Learnings

This initiative offered an opportunity to learn more about the needs of and challenges faced by older adults (especially those with serious illnesses), family caregivers and care partners when making healthcare decisions and navigating the healthcare system. It also offered the opportunity to build upon previous shared decision-making initiatives undertaken by FAIR Health. Both the quantitative and qualitative data reinforced the need for shared decision-making tools that incorporate cost information and additional tools, such as patient checklists and resource links for older adults, family caregivers and care partners.

## **Utility of the Older Adults Section Content, Shared Decision-Making Tools and Resources in Advancing Shared Decision Making**

Data collected from Google Analytics and survey responses point to the utility of the FAIR Health Consumer Older Adults section, shared decision-making tools and resources in advancing shared decision making among older adults, family caregivers, care partners and providers. Between September 2022, when the FAIR Health Consumer [Older Adults section](#) was launched, and December 2022, 10,312 unique users collectively visited the tools for older adults on FAIR Health Consumer and FAIR Health Provider: The Older Adults section of FAIR Health Consumer was visited by 9,700 unique users while the tools for older adults on FAIR Health Provider were visited by 612 unique users. Moreover, the Older Adults section of FAIR Health Consumer recorded 3,640 toolkit downloads, while the Patient Materials section of FAIR Health Provider received 780 visits and recorded 484 downloads of the toolkits by providers during the same period. Among the individuals surveyed, 74 percent found the tools, content and resources “useful” or “very useful”; 67 percent agreed that the Older Adults section increased their knowledge and understanding of shared decision making; 67 percent agreed that using the tools and resources made them feel that they could take part in shared decision making with their healthcare team or provider; and 65 percent of survey respondents agreed that the Older Adults section helped them to better understand how to manage their healthcare costs.

# Program Learnings

Likewise, qualitative feedback from patients, family caregivers, care partners and providers indicated the utility of the tools, content and resources in navigating the healthcare system, preparing for clinical visits and providing a fuller picture of treatment options and costs associated with care. Although the degree of familiarity with shared decision making and the shared decision-making tools differed among the participants, most participants expressed their appreciation for the tools, content and resources as they helped participants conceptualize different approaches to healthcare decision making. One provider remarked:

The good news is, is what you're all doing, you're providing an avenue to have these types of decisions. What you built, right, is to have us thinking more about it, and that's becoming the language now anyways, shared decision making, and you've made it more possible to have that conversation by doing what you did.

This sentiment was echoed in a remark made by a family caregiver:

For me, just looking up the [total treatment cost scenario], helped me see there's all the things my care recipient could benefit from, so having that discussion with the provider, to say, for example, "Should my mom get physical therapy?" ...I'm not utilizing all the resources she could possibly have. It just gives me all the options I could think about.



# Program Learnings

## Shared Decision Making as a Vehicle for Patient Empowerment

Another benefit of the tools, as indicated by the qualitative data, is their capacity to engage patients in healthcare decision making. The belief that the tools and, to a larger extent, shared decision making could be potential vehicles for patient empowerment was prominent in discussions with family caregivers, care partners, patients and providers. One provider stated:

With the Baby Boomer population, they want to know, we want to know, so we're very conscious of that. And we're conscious of making sure there's going to be money available for our children and grandchildren....I see that with all my friends and colleagues, as we continue to age, like everything we're putting into place, and everything that we're learning, we want to make sure that our children and our grandchildren are going to be able to get continued good healthcare, right. And that's why we have to keep the cost down. That's why we have to have shared decision making—that we have to have a goals of care conversation. So we're good stewards of the resources that have been given to us, and we have less waste.

This was echoed in a comment made by another provider: "It's very promising because it really gives them decision-making capability so they can compare and know what they're going to be paying out of pocket, how much money they're going to spend, and whether it's something that they need to do to invest money in." Similarly, patients who were interviewed emphasized that proper education and guidance give them and their peers agency in their healthcare decision making. Overall, participants across all groups seemed to share the notion that the tools had the potential to foster equitable patient-provider relationships.

# Program Learnings

## Frustrations around Healthcare Costs, Billing and Lack of Transparency

The qualitative feedback also pointed to a growing frustration with healthcare costs, the billing system and, in general, a lack of transparency in the healthcare system. Among patients, providers, family caregivers and care partners, the aforementioned factors were hindrances to accessing care and other services, especially by older patients with fixed incomes. For patients in particular, healthcare billing—including the time it takes to receive a bill for a healthcare service—was viewed as a source of frustration:

The other part that I have a problem with on healthcare bills is I get a bill six months, seven months after I've been to the doctor or they've done whatever they gonna do, and when I ask... 'cause I have Medicare, Blue Cross-Blue Shield also, and when I ask about it, they'll say, "Well, this is when your doctor sent it in." And then the doctor says, "Well, I send it in a certain, certain time." I just think that there should be something that doctors need to bill that needs to be mandatory that they bill within a thirty-day period, not six months down the line or nine months down the line. It's horrible! And then you're saying, "Well, what was this? I don't remember getting this." Then when you call and find out that oh, that was for a bunionectomy or whatever, you know, but they've used some other medical term that you have no idea what it was. So, they need to do something about the billing system and making the information easier for you to understand this is what we did on this day, this is how much it costs, whatever. This is what Medicare paid. This is what Blue Cross paid. This is what you owe. You know, because you pay a copay when you go in. It's usually \$40, then you still get a bill after you pay a copay... That only pays for this part, and you'll have to pay for this part. It gets frustrating—very frustrating.

Reflecting on their healthcare costs, some patients voiced their desire for more cost transparency and changes to the healthcare billing system.

# Program Learnings

## Importance of and Need for Support, Information and Resources

Both the survey responses and qualitative feedback from focus group participants supported the need for educational materials, resources and supports. Ancillary materials, such as checklists and links to external resources, were particularly popular among survey respondents and focus group participants. When asked which features were most helpful for their decision making, most chose resource links to external organizations and websites (48 percent) and [FH Healthcare Toolkit](#) checklists and articles (39 percent). Moreover, patients, family caregivers and care partners found the content and resources were helpful for navigating the healthcare system. Family caregivers, care partners and patients described at length their experiences navigating the healthcare system to find information, support and resources. Although some patients, family caregivers and care partners received adequate information and support from their providers, others did not, leading them to seek information from individuals in similar situations. Obstacles to finding information, support and resources—for clinical conditions and coverage—led to feelings of frustration and helplessness for some participants:

Because you can't be effective if you don't understand what's going on. And that's the problem. You walk out of there, and you're both just devastated. And I didn't know anything at all. And so I didn't know what to expect, I didn't know how to react, didn't know what to do that would be positive.

In recollecting their experiences, some patients, family caregivers and care partners voiced their dissatisfaction with the healthcare system. This is in line with findings from the February 2022 consumer survey report, which also described the obstacles older patients, family caregivers and care partners encounter as they navigate the healthcare system to find care. Most of the family caregivers and care partners surveyed in that report expressed their support for information, resources and tools that would help them learn how to make better decisions about their care receivers' care, understand healthcare costs and clinical information, outline different models of care and care choices with costs and assist them with healthcare navigation.<sup>24</sup>

# Program Learnings

## Barriers to Shared Decision Making

In addition to a lack of transparency in costs and information related to clinical conditions, focus group participants also indicated time constraints, lack of technology access and low health literacy as barriers to shared decision making. Most participants believed the tools to be beneficial, but some noted that they would need more time with providers to utilize them in care settings. However, despite the time constraints, most providers who were interviewed believed that they could incorporate elements of the tools during their visits with patients. During discussions, they expressed their eagerness to promote awareness of the tools and brainstormed various methods, which included incorporating links to the tools and information into patients' electronic health records and creating a curriculum centered on shared decision making for healthcare providers, students and fellows.

Focus group participants, particularly older patients, also indicated low health literacy as another barrier to healthcare access and shared decision making. During focus group discussions, many patients recalled the difficulties their peers faced when navigating the healthcare system with little knowledge and understanding of medical terms and verbiage. In those situations, they indicated many of their peers often deferred healthcare decision making to their providers. Further dialogue with patients reinforced the need for more supports for older adults with low health literacy. This finding is consistent with those from previous studies and FAIR Health's February 2022 consumer survey report, which revealed that older adults' ability to navigate the healthcare system and make informed decisions corresponds with educational attainment, household income and ethnicity.<sup>25</sup>

For patients in particular, access to technological devices also affects healthcare management and engagement. During these discussions, patients also recalled the struggles their peers faced when trying to access healthcare information. In addition to not understanding medical terminology, most older adults, as noted by some of the participants, do not have access to technological devices. For some of the patients interviewed, the inability to access technological devices, especially when seeking information related to care, created a fear of being "left behind." Moreover, some patients believed that older adults who do not have access to technological devices would not be able to use the tools.

# Conclusion

Shared decision-making tools with cost information and resources continue to demonstrate great promise for improving healthcare engagement and decision making in adults aged 65 and older, family caregivers and care partners. The initiative funded by The John A. Hartford Foundation enabled FAIR Health to develop and disseminate shared decision-making tools, resources and educational content relevant to older adults with serious health conditions and their family caregivers/care partners in an effort to better understand the demand and need for financial health literacy tools that provide cost information.

Program findings indicate a growing appetite and appreciation for tools such as these. Most of the older patients, family caregivers, care partners and providers interviewed and surveyed by FAIR Health believed that the tools were most helpful for developing their knowledge of shared decision making, understanding their healthcare costs and navigating the healthcare system. Moreover, some patients, family caregivers, care partners and providers viewed the tools as a vehicle for patient empowerment.

Findings also indicate that shared decision-making tools and resources remain novel to most consumers and providers, suggesting that more work needs to be done to increase consumer and provider awareness of the tools and facilitate their integration in clinical settings. The successful dissemination and outreach campaign implemented during the grant provided FAIR Health with a road map upon which it will further develop best practices that will be leveraged for future shared decision-making initiatives. Long term, these program findings, coupled with ongoing dissemination, may also encourage policy discussions among relevant and engaged stakeholders regarding the broader dissemination of shared decision making in diverse settings.

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# 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 40 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](https://fairhealthconsumer.org) and [fairhealthconsumidor.org](https://fairhealthconsumidor.org). For more information on FAIR Health, visit [fairhealth.org](https://fairhealth.org).

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