

One in four adults reportedly skip care due to high costs

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As part of an initiative funded by The John A. Hartford Foundation, FAIR Health conducted a nationwide study comprising two surveys geared toward older patients (adults 65 and older) and family

caregivers/care partners. The surveys revealed critical insights into the needs of older adults and their caregivers/care partners concerning healthcare navigation and decision making. The survey findings have been published in FAIR Health's new white paper, *Healthcare Navigation and Decision Making: Perspectives of Adults Aged 65 and Older and Family Caregivers*.

Key survey findings

FAIR Health conducted two separate surveys: One with older adults aged 65 and older and one with family caregivers/care partners aged 18 and older. The surveys, conducted in collaboration with ENGINE Insights, were fielded in November 2021 and reached 1,005 older patients and 507 caregivers/care partners. Each survey asked respondents about the importance of [healthcare costs](#) to decision making, attitudes toward shared decision making, barriers to informed decision making and healthcare navigation, and navigation of the healthcare system and needs for resources and tools. Analysis of the results revealed the following:

- One in four older adults (aged 65 and older) never know the costs of healthcare services before getting a bill. Although 32 percent of older adults reported that they "sometimes" know the costs of healthcare services before receiving their bill, 25 percent of older adults reported that they "never" know costs of healthcare services before receiving their bills, while 21 percent reported that knowing their healthcare costs in advance depended on whether the care was given by healthcare providers in their health plan networks or those not in their health plan's network.
- A significant proportion of older adults consider healthcare costs to be an important factor when making healthcare decisions; more than a third have difficulty getting such cost information. Thirty-seven percent of older adults felt that healthcare costs are

an "important" factor when making healthcare decisions, while 22 percent felt that it was the "most important" factor when making healthcare decisions. Sixteen percent of older adults reported that healthcare costs were "a thought" when making a healthcare decision, while 24 percent reported that they do not think about out-of-pocket cost when making a healthcare decision. However, 35 percent reported that they found getting information about their healthcare costs to be "somewhat hard" or "very hard."

- While a significant proportion of family caregivers/care partners consider costs to be an important factor in making decisions about the person for whom they provide care (their care receiver), most do not discuss costs with healthcare providers. Sixty-four percent of caregiver respondents felt that healthcare costs should be "important" (34 percent) or "most important" (30 percent) to their care receivers' healthcare providers and/or teams. Twenty-four percent of caregiver respondents reported that they did not want the healthcare provider to think about out-of-pocket costs in decisions about their care receiver's care. However, only 42 percent reported that they discussed those costs with their care receivers' healthcare providers and/or teams. Among the subset of caregiver respondents who reported that they do not discuss costs with their care receivers' healthcare providers and/or teams, 64 percent would not like to engage in such discussions.
- Despite a strong interest in having shared decision-making discussions, just under a third of [older patients](#) do not have such conversations with their healthcare providers and/or healthcare teams. Forty-five percent of older adults are "interested" or "very interested" in having shared decision-making discussions with their healthcare providers and/or healthcare teams. Moreover, 41

percent reported that they "always" or "often" take part in such discussions with healthcare providers. However, 29 percent reported that they have "never" engaged in shared decision making with their healthcare providers.

- Among older adults, encountering difficulties in obtaining cost information may be an obstacle to accessing needed healthcare. In response to the question, "How easy is it to get facts and see what your healthcare costs will be?" 35 percent of respondents said that it was "somewhat hard" or "very hard" to do so. Of this group, 27 percent reported that this difficulty got in the way of their ability to access needed care and 21 percent reported that it discouraged them.
- Over one in four (26 percent) older adults reported putting off or skipping needed healthcare due to cost. Older adults with lower household incomes were more likely to report forgoing needed care compared with older adults with higher household incomes. Thirty-two percent of older adults with household incomes below \$50,000 reported that they skipped getting needed healthcare due to healthcare costs. This compared with 19 percent of older adults with household incomes between \$50,000 and \$100,000 and 16 percent of those with household incomes above \$100,000.
- Family caregivers/care partners have a significant need and appetite for healthcare information, resources and tools that help them make better decisions about their care receivers' care. When asked about the kinds of information, resources and tools that would help them make better decisions about their care receivers' care, most caregivers/care partners selected information about providing better care for their care receivers (42 percent) and costs of care (40 percent), followed by clinical information (35 percent), educational training to help care

partners steer through the healthcare system (33 percent), information about different models of care that can coordinate different services (31 percent) and tools that outline different care choices with costs (30 percent). Most caregivers/care partners would prefer to access such information, resources and tools via a website (63 percent) or an app on a mobile device, like a phone or tablet (45 percent), with the opportunity to print paper copies from a website (39 percent).

In 2021, The John A. Hartford Foundation awarded FAIR Health funding for "A National Initiative to Advance Cost Information in Shared Decision Making for Serious Health Conditions." The 18-month initiative will expand FAIR Health's existing shared decision-making tools, which are currently focused on palliative care scenarios, through the creation of four new decision aids related to the care of older adults. The decision aids will combine clinical and cost information focused on treatment options for early-stage breast cancer, fast-growing prostate cancer, spinal stenosis and hip osteoarthritis. As part of the planning grant, later this year, FAIR Health will also launch new "total treatment cost" scenarios highlighting the range of costs associated with three conditions particularly relevant to an older population: Alzheimer's disease/dementia, heart failure and major depression. These tools will be accompanied by educational materials and resources that support both older adults and family caregivers in navigating the healthcare system.

FAIR Health President Robin Gelburd said, "FAIR Health's surveys have confirmed the importance of providing objective, unbiased healthcare cost information and engagement tools to consumers. The surveys' findings underscore the need and appetite for shared decision-making tools and resources that can help older adults and their caregivers/care partners make informed healthcare decisions, navigate the complexities of the healthcare system and improve their health insurance literacy."

The John A. Hartford Foundation Vice President of Program Rani E. Snyder said, "We applaud FAIR Health's work to address the barriers that affect healthcare decision making for older adults and their family caregivers. Findings from FAIR Health's report show that lack of information about costs can lead to obstacles in accessing needed care. Older adults and [family caregivers](#) need healthcare engagement tools that incorporate reliable cost information."

More information: The report is available as a PDF at [s3.amazonaws.com/media2.fairhe...per/asset/Healthcare%20Navigation%20and%20Decision%20Making%20-%20A%20FAIR%20Health%20White%20Paper.pdf](https://s3.amazonaws.com/media2.fairhealth.org/per/asset/Healthcare%20Navigation%20and%20Decision%20Making%20-%20A%20FAIR%20Health%20White%20Paper.pdf)

Provided by FAIR Health

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