When Cancer Screenings Are Free but Follow-ups Aren't, Patients Foot the Bill

Plus, a court ruling has the potential to invalidate required free screenings, including for breast, colorectal, cervical and lung cancer.

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If you've gotten a free cancer screening in the past decade, you likely have Dr. Mark Fendrick to thank. Fendrick is an internist and director of the Center for Value-Based Insurance Design at the University of Michigan.

"I have to tell you that the intuitive idea of having more of the good stuff in health care and less of the bad stuff, did seem to be pretty well-received," he said of the 15 years he's spent pushing state and federal policymakers to see the benefits of health care screenings – and to pay for them.

Fendrick helped design a popular part of the Affordable Care Act that made nearly 100 preventive care services free, including screenings for some of America's deadliest cancers: lung, cervical, colorectal and breast cancer.

Before the ACA, people with private insurance could spend $600 on average for colonoscopies that screened for colorectal cancer. The free screenings represented a huge step forward.

But by 2016, Fendrick began to see a major flaw in the part of Obamacare he helped write.

Only the first screening tests — in the case of colorectal cancer, it could be an inexpensive at-home test — were paid for.

To actually diagnose cancer, most patients need follow-up tests. Research shows these secondary tests for lung, colorectal, breast and lung cancer can cost on average between $100 and $400 out-of-pocket.

"The emotional toll of being told that your first test is positive and you may have cancer is huge. Add on top of that a financial burden that might put you in dire straits, leading you to give up on food, rent or gas," Fendrick said. "This infuriates me."

Fendrick thought regulators and health insurers had distorted the original intent of the preventive care provision, which was to make the entire diagnostic process free, so he started rounding up his

Affordable Care Act allies to see what a fix could look like.

Reducing Disparities by Covering Follow-up Screenings

Around the same time, in Oregon, advocates for colorectal cancer had been working to change state policy to make follow-up colonoscopies free to patients.

Gloria Coronado, an epidemiologist at Kaiser Permanente Center for Health Research, studies disparities in colorectal cancer screening.

Shortly after the ACA passed in 2010, she was encouraging community health centers in Oregon to recommend easier at-home screening tests. Clinicians hesitated to promote testing because of expensive follow-up tests for low-income patients.

Coronado brought this problem to an influential Oregon lawmaker, who led the effort to update state law in 2014 to require both Medicaid and some private insurance plans to make follow-up colonoscopies free for patients.

In 2017, three years after Oregon's new law, the 40 percent disparity in colorectal screenings between Medicaid patients and people with private insurance vanished. Data also showed the state's community health centers, which serve some of the state's poorest patients, were doing more of these screenings than their peers in neighboring states. Eight states soon passed similar laws.

By 2021, federal screening guidelines were updated to include follow-up colonoscopies. That laid the groundwork for regulators to start forcing private insurance companies to cover these tests for colorectal cancer this year. Medicare is expected to follow suit beginning in 2023.

Spending on Tests Could Save Money

One reason colorectal cancer advocates succeeded is because this policy may save insurance companies money. With the first screening and follow-up test fully covered, Fendrick projects more people are likely to take the less expensive at-home tests, and he argues costs of covering that second round of screenings will be offset.

"Because most people are negative, the math just works out in a way that if you waive cost-sharing for follow-up, it is actually made up by getting more people to get less expensive initial tests," he said.

Cheaper, reliable at-home screening tests don't yet exist for lung, breast and cervical cancers. However, home tests are in development for human papillomavirus, or HPV, the virus that causes cervical cancer.

Advocates for cervical and lung cancer are in the early days of tackling this follow-up coverage dilemma.

Meanwhile, breast cancer advocates have made progress for the estimated 12 million women who get follow-up procedures each year. At least ten states have passed laws requiring coverage for more testing.

“The only opposition we’ve seen are [insurance companies],” said Molly Guthrie, vice president of policy and advocacy at Susan G. Komen, a breast cancer advocacy organization.

She said the group plans to introduce bills in several more states, including Florida, Missouri and Iowa, next year.

If more states move to require insurers to fully cover tests for the other three cancers, companies would likely pass those costs along to health care consumers in the form of higher premiums.

It is difficult to gauge insurers’ interest in paying for tests to confirm a diagnosis. Representatives from UnitedHealthcare and the industry trade group AHIP said in emails they support the ACA screening guidelines and covering costs for additional colorectal screenings.

Legal Challenges Threaten Screening Coverage

A court ruling from September has the potential to invalidate the required free cancer screenings.

A federal district court judge in Texas ruled the key part of the ACA that requires insurers to fully cover these cancer screenings is unconstitutional. The judge said that since the U.S. Preventive Services Task Force, a 16-member panel of independent experts, was not appointed by the president and confirmed by the U.S. Senate, the Task Force lacks standing to set coverage policies for insurers.

The case is moving through the courts, but if the decision stands, the country could return to the days when individual insurers could decide which, if any, screening tests to cover.

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