# **High Cost of Diagnosing Breast Cancer Prevents/Delays Needed Care**



Study Shows Women Delay or Avoid Diagnostic Exams Due to High and Uncertain Out-of-Pocket Costs

Millions of women across the country now have access to free screening mammography, thanks to its inclusion as a required essential benefit under the Affordable Care Act (ACA). However, if the results of that screening mammogram suggest the need for a follow-up exam to determine if the woman has breast cancer (which may be as many as 10% of all women screened), she may be faced with hundreds to thousands of dollars in out-of-pocket costs — all before she ever gets to treatment.

A new study conducted by The Martec Group for Susan G. Komen<sup>®</sup> shows the high and often varying costs for diagnosing breast cancer, which causes women to become frustrated and delay, or even forego, the needed exams, sometimes with tragic consequences.

### What are Women Actually Paying?

	All Patients		Medicare <sup>b</sup>	Private to Medicare ${f Transition}^{\circ}$	
	Average	Average	Average	Average	
Diagnostic Mammography	\$234	\$239	\$172	\$229	
Breast Ultrasound	\$95	\$100	\$54	\$83	
Breast MRI	\$1,021	\$1,073	\$615	\$954	

# **Key Learnings**

The Martec Group conducted more than 30 in-depth interviews with health care professionals and women who have been impacted by the cost and coverage of breast diagnostics. Overall, patients, insurance professionals and health care providers reported that cost and confusion about coverage of diagnostic imaging leads to frustration and forces patients to delay or avoid the exams.

- Women are often unsure of what to expect due to variations in coverage and cost, leading to frustration, confusion and sometimes avoidance - often while their cancers progress, reducing treatment options and survival chances.
- 2. **Unexpected costs** cause many women to cancel or delay their doctor recommended diagnostic tests, waiting on either **better coverage**, **savings or when they can feel a lump on their own.**
- 3. Mammograms aren't always sufficient in detecting cancer and insurance coverage should reflect that.

a Commercial: data from active employees, early retirees, health care coverage under the Consolidated Omnibus Budget Reconciliation Act of 1985 continues, & dependents insured by employer-sponsored plans (i.e., persons not eligible for Medicare). b Medicare/Medicare supplemental: data from individuals enrolled in Medicare who also have group health insurance coverage paid for by a current or former employer. c Transition: data for patients who transitioned during the reporting period from having only commercial insurance to then having Medicare plus a supplemental insurance paid for by their current or former employer

# Understanding Cost & Coverage Issues with **Diagnostic Breast Imaging**





The following report represents key findings from The Martec Group's primary and secondary research efforts. The team was instructed to explore the cost and coverage issue with breast diagnostic imaging in order to equip Susan G. Komen with the information necessary to strategize efforts at the state and federal levels.

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#### I. A Brief Summary of Findings

Patients, insurance professionals, and health care providers recognize the cost and coverage issue with diagnostic imaging. Cost is perceived as an added stressor and often leads to frustration, prioritization, and avoidance for patients. Although some insurers cover additional diagnostic imaging (MRIs, ultrasounds, etc.), the costs vary so much across the board that women are confused and often misguided. With nearly 50% of women receiving a second procedure after their initial diagnostic test, Martec concludes that additional coverage needs to and should be considered.

#### **II. Project Background**

Susan G. Komen was seeking proposals from firms and/or individuals to conduct an analysis of coverage and cost for breast diagnostic imaging (mammography, ultrasound, magnetic resonance imaging) in different health insurance types - Medicare, Medicaid, and private coverage. Diagnostic imaging is used to check for breast cancer after a lump or other sign or symptom of the disease has been found clinically or on screening mammography. Diagnostic imaging is also typically recommended for asymptomatic women that have undergone a lumpectomy followed by radiation therapy and those with a prior history of breast cancer.

Diagnostic imaging is typically more expensive than a screening mammography. As a result, patients are often burdened with co-pays and other cost-sharing when receiving diagnostic imaging, unlike with screening mammograms which are fully covered by Medicare, the Affordable Care Act (ACA) plans and most private plans.

For women who receive abnormal results on a screening mammogram, reducing out-of-pocket costs for diagnostic imaging would improve access and utilization, and allow more timely diagnosis and treatment of breast cancer.

This analysis defines the problem in all health insurance types across the country and provides supplemental stories from women who have faced this challenge.

# **III. Study Objectives**

The objectives of the study included the following:

- Provide informative, national aggregate data and bell weather State data (targeted from the following group: TX, CA, IL, FL, OH and MA), related to breast diagnostic imaging (mammography, ultrasound, magnetic resonance imaging) coverage and cost in different health insurance types - Medicare, Medicaid, and private plans
  - "Best efforts" basis targeting ~5 representative States as data may not exist in all cases
- Develop a cost analysis on the findings of screening mammography and diagnostic imaging coverage and how this influences the following:
  - Patient access
  - Out-of-pocket costs
  - Treatment delays/time to diagnosis

# IV. Research Methodology

In-depth primary research with key decision makers (healthcare industry) and women facing this problem drove the engagement.

Martec engaged with multiple functional decision makers across the diagnostic imaging (mammography, ultrasound, magnetic resonance imaging) and insurance industries.

Secondary research also supported the engagement and educated/informed Martec researchers prior to the primary in-depth interviews:

Martec collected and incorporated the relevant published data into this report.



#### **V. Patient Perspective**

In-depth interviews with women from five targeted states (TX, CA, IL, FL, OH and MA) shed light on the issue. Four reoccurring themes were uncovered throughout Martec's phone interviews:

- 1. With diagnostic imaging costs varying so much across the board, women are unsure of what to expect—leading to frustration, confusion, and sometimes avoidance.
  - Elayne from Columbus, OH [Medicaid] "It's not fair to people when they have to make the choice between getting mammograms and ultrasounds vs something else...like paying rent or for their kids' lunch."
  - Krista from Wellesley, MA [Tufts] "I just found out my scheduled breast MRI is not covered by my insurance. So it seems like I have three choices right now—cancel my MRI, private pay, or appeal the decision...which takes I don't know how long. I'd consider the private pay option, but no one can give me an estimate...doctors have no idea. Everyone throughout this whole process seems to be in the dark—as if they haven't done this a million times before."
  - Stephanie from Cyprus, TX [Cigna] "He wants me to do a Diagnostic Mammogram...! asked them about out-of-pocket charges...! would have to pay \$430 and that doesn't include radiologist charges and other separate charges. This really pisses me off because they want us to do screening each year but then the cost is getting higher which makes it pretty hard to afford. I know I paid half that price last year."
- 2. The process of getting tested is already stressful—women view the unexpected costs as a "cherry on top" and yet another aspect of the experience to dread. Some even believe the cost is getting worse over time.
  - Raechael from Chino, CA [Blue Cross Blue Shield] "It's already a really scary process—finding a lump, getting tested, waiting for results...wondering if I'll be paying off my bills for the next few years is just the icing on the cake. It's a lot to handle."
  - Jan from Palo Alto, CA [Health Net & Cigna] "I was referred for a mammogram and ultrasound for a lump that my primary doctor found. Because I'm about a year too young, by insurance covers nothing. I struggled to pay \$1,200 combined."
  - Ebonie from Chicago, IL [Humana HMO] "I used to have Blue Cross Blue Shield and we didn't have a copay for normal mammograms but even then, I still paid \$1700 because the no-cost mammogram lead to ultrasound, another mammogram, and an MRI. But Humana, which I have now, is even worse because I have a \$50 copay just for screening."
- **3.** Many women decide to cancel or delay their doctor recommended diagnostic tests when they find out the cost—either waiting for better coverage or until they can save up enough money. Others are jaded by past prices paid and will only return for testing if they feel it is necessary (i.e. finding a lump on their own).
  - Kristen from Lagrange, IL [Blue Cross] "Since I just got checked out, I probably won't go back for at least 3 or 4 years.

    The copay is so high for specialists, and even for my primary care doctor, so I'll only go if I think I feel something again."
  - Theresa from San Francisco, CA [Anthem Blue Cross] "I have extremely dense breasts and every time I have a mammogram or a breast exam, the technician or medical personnel comments that I would be better off having a 3D mammogram. Since my insurance won't cover a 3D until the regular mammogram comes back in question, the cost-prohibitive 3D exams will not be covered, so I haven't had one. Recently, I had genetic testing as part of a mammogram/breast study, and the results came back as my having a gene (not the BRACs) that are indicating a very increased risk for breast cancer. I was scheduled for a breast MRI in October, but when I found out that I would first have to meet my \$500 deductible and then still have to pay even more (insurance will only cover 80% until I meet the \$2500 max out of pocket), I ended up cancelling that procedure. I still haven't gotten it because I can't afford it right now."
  - Annie from Wylie, TX [Medicaid] "I'm a 14-year breast cancer survivor, so you think I'd be able to afford at least a yearly mammogram. But Obamacare is terrible. It doesn't cover hardly anything. I've been waiting a few years to get checked again because in March I qualify for Medicare and I've heard that's better."
  - Nancy from Chicago, IL [No insurance] "Prior to beginning my job in June, I was a contractor and responsible for covering my own medical costs. Hence, I put off having an MRI (breast mammogram) until approximately two years ago when I turned 48, as I did not want to pay out-of-pocket."
  - Brittany from Chicago, IL [Aetna PPO] "I had to pay \$549 out of pocket for my ultrasound, but they let me pay it off monthly. I'm still making payments. It makes me hesitant to go in the future.... knowing how much it will cost me makes me think, maybe I can put it off a little longer until I get my finances together... Some of my friends are even hesitant to go to the gyno because they think everything will cost too much. They want to wait until they feel something."

- **4.** The process has made women feel undervalued and unprotected when neither the medical or insurance industries will fight for lower prices.
  - Jean from Freeport, TX [No insurance] "I felt in the dark during the process because no one was being straight with me when I asked about how much the MRI would cost. The fact that it's not covered makes me frustrated as a woman and really not valued in the medical or insurance industry."
  - Laura from Tarpon Springs, FL [Florida Blue] "They [her insurance company] paid a little more after I called and made a big fuss about it—but they don't really care. I struggled to pay the \$350 I talked them down to."
  - Andrea from Evanston, IL [Medicaid] "The whole process was frustrating—financially and emotionally. So much that I questioned whether these tests were doing any good or if the healthcare industry was just trying to nickel and dime me."
  - Lo from Maitland, FL [Blue Cross Blue Shield] "I had to go around to almost a dozen different local doctors to find one who would fight for me and try to get me a lower price for the ultrasound. Most accepted that the screening mam was all that would be covered."
  - Michelle from Hollywood, FL [Medicaid] "We're not doing this for fun. There are so many things I'd rather spend money on, but it has to be done. Breast cancer is one of the scariest things, so what am I supposed to do....it isn't right that something all women eventually have to do isn't covered."

As echoed in verbatim responses, women are struggling with the cost and coverage of breast diagnostic imaging. They are frustrated, confused, which often leads to avoidance of an already emotional and stressful medical decision...a decision that can be crucial in detecting breast cancer.

#### VI. Health & Insurance Professional Perspective

To gain another perspective, Martec explored the opinions of healthcare and insurance professionals. Like their patients, professionals also see flaws in not only the cost and coverage of diagnostic imaging, but also the process. The following opinions were echoed:

- 1. Cost was defined as the primary reason women avoid diagnostic imaging or don't follow-up after their initial screening mammogram. Often secondarily, lack of education and mental health were mentioned.
  - "Too many women fall to the wayside because they can't afford a follow-up, then they forget about it or can't afford to make it a priority."
  - "I have a lot of women who don't come back...say you have a biopsy that turns out negative. We want you to come back 6 months later for a short-term follow-up...but many women don't come back for that follow-up because their insurance won't cover it."
  - "Our biggest problem that prevents our patients from following-up are social and mental health issues (depression, PTSD, homelessness, substance abuse) not cost."
  - "I have women who refuse to get ultrasounds because they don't know what it's gonna cost."
- 2. They agree that screening mammograms aren't always sufficient in detecting cancerous tissues and insurance coverage should reflect that.
  - "Mammography isn't foolproof...a lot of times that ultrasound can pick up cancerous tissues that a mammogram can't miss. But when insurance only covers that mammogram, it's telling these women that it's all they need."
- **3.** But professionals also believe women need to hold themselves more accountable throughout the process. Not only do they need to be knowledgeable about the risks involved with skipping a screening, but they should also be more aware of their resources.
  - "So many people don't know that they can call up their insurance company and demand that more gets paid for. And why would they? Nobody is telling them these things.... but the insurance companies don't care. They'll work with you if you care enough to call."
  - "They need to take more responsibility for themselves. There are so many resources out there...especially for women with low income...these women are avoiding these tests because they think they can't afford it or don't know how much it's going to cost, but there are other ways....it doesn't always work out, but it's worth a shot."
  - "A lot of primary care doctors don't get involved in things like that [educating women on their options] ...so that's definitely part of the issue."
  - "More women need to know what they're entitled to if they don't have insurance."



- "Women need to be asking about what other fees are involved...like a reading fee...and feel comfortable negotiating costs."
- "I wish I could tell every woman, 'If you don't know who to call or you can't speak English, have someone help you.'"
- 4. In the end, they offered a few heartbreaking anecdotes that shed light on how big of an issue this really is.
  - "It's a business...and if patients get cancer then the insurance company is guaranteed a steady stream of income at least for the next couple of years. It's terrible, but that's how it's set up."
  - "In 2015 I had a young girl come in...probably about 32, full-figured with large breasts, two young children, she came in with a lump. She said she had it for 6 months, but her husband was self-employed and the deductible was way too high, so she had to wait for him to have an off-year salary-wise. It turns out that in that 6 months, she developed metastatic breast cancer and passed away 18 months later...leaving her husband and two small children behind.... she was young. Six months of development could be the difference between stage one and stage four... I can still picture her mother in the waiting room after her biopsy just crying her eyes out. It took me a long time to get over that."

# VII. Costs Analysis

The cost analysis portion was two-fold. First, Martec conducted secondary research to uncover previous work done in the field.

A study published in 2018 illustrated the utilization and associated costs of breast imaging and diagnostic procedures after a screening mammography (Vlahiotis et al., 2018).

Vlahiotis' study used health care claims data from 2011 to 2015 so researchers could follow the path many women take after their screening mammogram:

"The most common first diagnostic procedures were diagnostic mammography for 88.0% of patients and ultrasound for 10.8%. Following the first procedure, 49.4% of patients proceeded to a second procedure, which was most often ultrasound (57.4%) or diagnostic mammography (33.5%). Biopsy was performed for 6.3% of patients following their first diagnostic imaging procedure. Of the patients receiving a second procedure, 40.8% experienced a third round of diagnostic testing, most commonly diagnostic mammography (54.2%) or ultrasound (27.4%). Biopsy was performed for 13.8% of patients experiencing a third round of diagnostics. Half of the patients with three diagnostic procedures went to a fourth round of procedures" (Vlahiotis et al., 2018).

Following their first diagnostic procedure, 49.4% had a second procedure, 20.1% had a third, and 10.0% had a fourth. However, the two most common paths are:

- Screening mammogram→Diagnostic mammogram→Ultrasound→Biopsy
- Diagnostic mammogram→Ultrasound→Biopsy

When the study's sample of 875,527 patients was projected nationally, there were "12,394,432 patients annually receiving 8,732,909 diagnostic mammograms (53.3% of patients), 6,987,399 breast ultrasounds (42.4% of patients), and 1,585,856 biopsies (10.3% of patients)."

And most relevantly, the study found the mean, median, and standard deviation of the amounts paid by patients for different breast diagnostic tests between 2011 and 2015 (see **Table 1**).

In Martec's primary research efforts, patients (women), healthcare professionals, and insurance professionals were asked what the going rate was for each of the following four tests: Screening mammogram, diagnostic mammogram, breast ultrasound, and breast MRI. The prices varied across the board but were in line with the national averages found in Vlahiotis et al.'s 2018 study (see **Table 2**).

The nationwide average patient cost for a diagnostic mammogram is \$349 (Vlahiotis et al., 2018), although women stated they paid anywhere from \$150 (without insurance in Illinois) to \$836 (BCBS PPO in Texas).

The nationwide average patient cost for a breast ultrasound is \$132 (Vlahiotis et al., 2018)—but some women paid nothing (Blue Cross in Massachusetts) and others paid \$755 (United Health Care in California).

Regardless of the diagnostic procedure, some women are paying far too much while others pay nothing at all. The inconsistency in cost and coverage is a recognized issue among both patients and health professionals.

# **VIII. Conclusions**

Based on these findings, Martec concludes the following:

- 1. The longer it takes for women to detect breast cancer, the quicker their five-year survival rates decline (Howlader et al., 2017). But frustration, fear, and confusion about follow-up costs can lead to avoidance and ultimately higher risk.
- 2. Over 12 million women are receiving follow-up breast diagnostic procedures each year, adding up to an annual expenditure of nearly \$8 billion (Vlahiotis et al., 2018). This study has provided further background into the issue and presents a clear need for funding to support 2nd, 3rd, and 4th line testing resulting from initial mammography results.
- 3. And lastly, there is a lack of appropriate education and awareness on testing costs and procedures among both women and healthcare professionals.

# IX. Appendix

**Table 1:** Mean, median, and standard deviation of paid amounts for breast diagnostic procedures by the patient (Vlahiotis et al., 2018).

	ALL PATIENTS		COMMERCIALa		MEDICARE <sup>b</sup>		TRANSITION <sup>c</sup>	
	n=875	,526	n=789,	062	n=73,7	768	n=12,6	96
	MEAN (SD)	MEDIAN	MEAN (SD)	MEDIAN	MEAN (SD)	MEDIAN	MEAN (SD)	MEDIAN
Diagnostic Mammography	\$349 (\$492)	\$234	\$354 (\$490)	\$239	\$297 (\$518)	\$172	\$347 (\$477)	\$229
Tomosynthesis	\$134 (\$102)	\$113	\$136 (\$102)	\$115	\$110 (\$102)	\$93	\$115 (\$88)	\$93
Ultrasound	\$132 (\$134)	\$95	\$137 (\$135)	\$100	\$76 (\$109)	\$54	\$112 (\$120)	\$83
Molecular Breast Imaging	\$296 (\$422)	\$135	\$299 (\$406)	\$133	\$291 (\$530)	\$190	\$175 (\$165)	\$77
Magnetic Resonance Imaging	\$1,197 (\$1,054)	\$1,021	\$1,228 (\$1,054)	\$1,073	\$875 (\$1,005)	\$615	\$1,130 (\$984)	\$954
Biopsy	\$1,938 (\$2,343)	\$1,211	\$1,940 (\$2,177)	\$1,246	\$1,901 (\$3,424)	\$918	\$2,064 (\$2,862)	\$1,154
Ultrasound- Guided Localization	\$1,909 (\$2,199)	\$1,245	\$1,902 (\$2,002)	\$1,276	\$1,951 (\$3,438)	\$971	\$2,075 (\$2,466)	\$1,105
Ultrasound- Guided FNA	\$249 (\$467)	\$153	\$251 (\$467)	\$154	\$240 (\$480)	\$146	\$208 (\$406)	\$118
Other FNA	\$217 (\$286)	\$172	\$220 (\$298)	\$173	\$193 (\$135)	\$159	\$173 (\$82)	\$181
Ultrasound- Guided Core	\$1,032 (\$1,200)	\$694	\$1,036 (\$1,077)	\$712	\$999 (\$1,950)	\$578	\$1,041 (\$1,407)	\$695
Follow-Up Office Visit	\$735 (\$891)	\$451	\$720 (\$886)	\$432	\$811 (\$926)	\$570	\$783 (\$807)	\$516
Pathology	\$1,264 (\$2,463)	\$501	\$1,243 (\$2,371)	\$502	\$1,381 (\$3,075)	\$471	\$1,682 (\$2,882)	\$660
Anesthesia	\$1,120 (\$1,146)	\$776	\$1,178 (\$1,143)	\$843	\$702 (\$1,058)	\$356	\$1,166 (\$1,312)	\$793

<sup>&</sup>lt;sup>a</sup> Commercial: data from active employees, early retirees, health care coverage under the Consolidated Omnibus Budget Reconciliation Act of 1985 continues, and dependents insured by employer-sponsored plans (i.e., persons not eligible for Medicare).

<sup>&</sup>lt;sup>b</sup> Medicare/Medicare supplemental: data from individuals enrolled in Medicare who also have group health insurance coverage paid for by a current or former employer.

<sup>&</sup>lt;sup>c</sup> **Transition**: data for patients who transitioned during the reporting period from having only commercial insurance to then having Medicare plus a supplemental insurance paid for by their current or former employer.

Table 2: Self-reported costs of each test based on primary in-depth interviews with patients, providers, and insurance agents—supported by secondary research.

	INSURANCE TYPE	TYPE OF TEST						
		Screening Mammogram	Diagnostic Mammogram	Breast Ultrasound	Breast MRI			
Texas	Without Insurance	\$65, \$170	\$638, \$1046	\$250, \$140, \$250, \$550	\$1303, \$2070, \$1609, \$950, \$2000, \$1275			
	Medicare	No cost if a doctor accepts the assignment 20% of the Medicare approved amount						
	Medicaid	No cost to the patient for any of these tests.						
	Private	Likely \$0 if over 40	\$336 (Blue Cross Blue Shield PPO) , \$430 (Cigna), \$836 (BCBS PPO), \$360 (Aetna)	\$350 (Cigna PPO), \$219, \$550 (Blue Cross Blue Shield PPO)	\$161 (Aetna)			
California	Without Insurance	\$210, \$80, \$330, \$160	\$290	\$336, \$350	\$795, \$2395, \$2190, \$3117, \$693, \$1174			
	Medicare	No cost if a doctor accepts the assignment						
	Medicaid	No cost to the patient for any of these tests.						
	Private	\$105 (Catholic Healthcare West), \$0 (Anthem Blue Cross), Capital Blue Cross (\$0), Likely \$0 if over 40	\$500 (Kaiser), \$1788, \$730 (Blue Cross), \$265, \$403 (United Health Care), \$469 (Health Net), \$300 (Aetna)	\$755 (United Health Care)				
Illinois	Without Insurance	\$90, \$100	\$150, \$660	\$270, \$145, \$110	\$295, \$425, \$1371, \$2139, \$1280, \$2041			
	Medicare	No cost if a doctor accepts the assignment 20% of the Medicare approved amount						
	Medicaid	No cost to the patient for any of these tests.						
	Private	Likely \$0 if over 40	\$627 (Aetna), \$660 (BCBS PPO)		\$250 (Blue Cross)			
	Without Insurance	\$99, \$143, \$250, \$100	\$185, \$168	\$145, \$106, \$135-240, \$127	\$620, \$527, \$2325, \$537, \$1239, \$1126			
Florida	Medicare	No cost if a doctor accepts the assignment	20% of the Medicare approved amount					
	Medicaid		No cost to the patient for any of these tests.					
	Private	Likely \$0 if over 40	\$550 (BCBS FL), \$187 (BCBS PPO)	\$100 (Blue Cross)				
	Without Insurance	\$70, \$170, \$93, \$160, \$80	\$345, \$400	\$130, \$330, \$440, \$110, \$750, \$370	\$775, \$1609, \$1750, \$1821, \$2027, \$1758,			
Ohio	Medicare	No cost if a doctor accepts the assignment	s 20% of the Medicare approved amount					
	Medicaid		No cost to the patient for any of these tests.					
	Private	Likely \$0 if over 40	\$300 (MediGold)	\$190 (MediGold)				
Massa- chusetts	Without Insurance	\$80, \$210, \$380, \$90, \$220, \$0	\$240	\$290, \$700, \$240, \$975, \$140	\$1663, \$1663, \$4173			
	Medicare	No cost if a doctor accepts the assignment	20% of the Medicare approved amount					
	Medicaid		No cost to the patient for a	any of these tests.				
	Private	Likely \$0 if over 40	\$500 (Blue Cross)	\$0 (Blue Cross)	\$100 (Blue Cross)			

Note: Certain data points were omitted because they were not found during the in-depth interviews or from secondary resources. Additionally, these costs were self-reported and may reflect bias and inaccuracy due to a lapse of time since the test and/or client misinformation.



#### X. Citations

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