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HOW INSURANCE COVERAGE DENIALS CAN BLOCK ACCESS TO PREVENTIVE AND EMERGENCY CARE

THE DOCTOR-PATIENT
RIGHTS PROJECT

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INTRODUCTION: COVERAGE DENIALS FOR PREVENTIVE AND EMERGENCY CARE

The Doctor-Patient Rights Project (DPRP) is a nonprofit coalition of doctors, patients, caregivers, companies and advocates fighting to restore the fundamental practice of medicine and to ensure doctors, in partnership with their patients, drive patient care decisions. We operate under the belief that third-party payers should partner with physicians to facilitate care and not impose healthcare decisions on physicians or patients. We pursue this mission by educating policymakers and the public about the dangers of corporate influence in medical decision-making.

In our 2017 report *Access Denied: How Utilization Management Protocols Can Block Access to Life-Saving Treatments*, DPRP evaluated five common "utilization management" (UM) techniques that are used by insurance companies to block patient access to care when applied in an overly broad or aggressive manner.

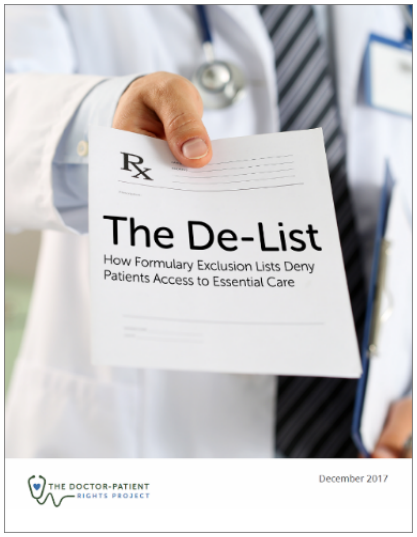
- Prior authorization requirements can saddle healthcare providers with significant and costly administrative burdens, and delay or deter patients from receiving prescribed treatments.
- Non-medical switching overrules the clinical judgement of treating physicians without any medical justification.
- Step therapy not only delays access to effective treatments, it can induce adverse drug reactions that jeopardize patient health and require costly, additional medical interventions.
- Adverse tiering can be used to circumvent anti-discrimination and often raise treatment costs beyond what some patient groups can afford.
- Formulary exclusions deny coverage for prescribed medication to patients with chronic illnesses—like diabetes and cardiovascular disease—or force them to switch medications in the middle of a coverage year.

According to DPRP's 2017 survey, as many as one-in-four (24%) insured Americans with a chronic or persistent illness have had coverage of a treatment denied as a result of these UM techniques.[1]

DPRP's first *Access Denied* report examined the overly aggressive application of UM policies to deny coverage for pharmaceutical treatments and some non-pharmaceutical alternatives. Following its publication, many groups contacted DPRP indicating that similar UM techniques are blocking access to preventive services (like medical screening, prophylactic interventions and genetic testing) as well as emergency care.

Globally, insurance companies now spend more than 60% of collected premiums on preventable chronic conditions.[2] Yet, as the incidence of chronic disease has risen, insurers have increasingly restricted access to medical services and treatments along the continuum of care. Despite provisions under the Patient Protection and Affordable Care Act (ACA) intended to guarantee full coverage of preventive care, DPRP members are concerned that insurers are still finding opportunities to restrict access to medical services that could prevent the development of many chronic diseases.

Once chronic diseases develop, insurers have erected barriers to medical services and care essentials for managing these conditions and increasingly exclude treatments for many chronic conditions from coverage altogether, as DPRP documented in the 2017 report, *The De-List: How Formulary Exclusion Lists Deny Patients Access to Essential Care.*



DPRP members have also been alarmed by reports that insurers are increasingly denying emergency care coverage often essential to patients suffering from advanced chronic conditions. There is a growing concern that recent changes some insurers have made to their coverage policies could seriously jeopardize access to emergency care for patients treating chronic diseases, if similar policy changes are adopted more broadly.

This report presents previously unreleased data from DPRP's 2017 *Not What The Doctor Ordered* survey on the number of patients being denied coverage for treatment of chronic illnesses and examines more specifically the challenges these patients face accessing preventive and emergency care. In addition, the report evaluates the long-term costs of restricting patient access to medical services that could prevent chronic conditions from ever developing and the emergency care often required to address chronic conditions once they have.

EXECUTIVE SUMMARY

Health insurers are using opaque and inconsistent standards to deny coverage for preventive medical services, including medical screenings, prophylactic interventions and genetic testing, as well as emergency services.

- Health insurers, rather than medical practitioners or policymakers, determine whether a preventive healthcare service is a "medical necessity" or if an emergency service, which may have been provided as part of a diagnosis, could have been "avoidable."
- These terms are the most commonly cited reasons patients are denied access to preventive and emergency health care services by their insurer.
- Denials are impacting patients across age, gender and ethnic demographics, increasing financial burdens on patients and creating barriers to care.
- Coverage barriers in individual categories of preventive care can lead to negative health outcomes even when other services are approved. For example, an insurer might cover a patient's medical screening for a certain disease and yet still deny coverage for a prophylactic intervention that would help prevent that disease.

According to DPRP's survey, insurers deny 1 in every 10 claims for medical testing or screening, which could impact as many as 7.7 million insured Americans.

- Around 40% of patients appeal denials of claims for testing or screening and a majority of those appeals—51%—are unsuccessful.
- The most common justification insurers provide for denying coverage of medical screening tests is that the denied procedure is "not medically necessary" (28%).
- For patients who had a claim denied by an insurer, 63% of Black patients reported receiving a denial for preventive tests and screenings, compared with 24% of Caucasians and 18% of Hispanic patients.
- For patients who had a claim denied by an insurer, 46% of those living in rural settings reported receiving a denial for preventive tests and screenings, compared to 41% of patients in urban areas.

Insurance companies create barriers to prophylactic interventions, even in cases where patients are considered to be at high risk for a serious health condition.

- The ACA requires some insurers to fully cover many preventive services but linking the mandate to the recommendations of the U.S. Preventive Services Task Force (USPSTF) creates coverage gaps for many patients.
- In many cases, the ACA mandates full coverage of medical tests and screenings to identify patients most at risk for chronic diseases but permits insurers to impose cost-sharing obligations or deny coverage for the prophylactic interventions necessary to prevent them.
- Out-of-pocket expenditures deter patients from utilizing preventive care.

Insurance coverage of genetic testing traditionally has been limited by the fragmented nature of the private insurance market.

- Early detection of chronic conditions can result in better clinical outcomes for patients and can cost as much as one-third less than conventional screening.
- A number of issues continue to create barriers for patients trying to access these services – including health plans being exempted from ACA requirements, idiosyncrasies in USPSTF recommendations, and complexities involved in determining the actual intent of preventive services.
- While exchange benchmark plans provide a potential mechanism for states to compel more consistent coverage of genetic testing and services, they can also often limit coverage of genetic testing and create greater interstate variability in coverage.

Patients are facing coverage denials for emergency care, including retroactive denials after receiving treatment from emergency departments.

- Insurers are exploiting ambiguous legal standards to deny patients in need of emergency care that can be classified as "avoidable," but only 3.3% of emergency department (ED) visits actually fit the insurance industry's own standard.
- Retroactive denials fail to acknowledge that individual symptoms can result in a wide range of diagnoses. A 2016 study found 52% of retroactive denials examined were ultimately overturned after independent review.
- Coverage denials for emergency care can saddle patients with significant debt, and 31% of households with medical debt failed to properly treat other health problems as a result.

PREVENTIVE SERVICES

INSURERS CREATE BARRIERS TO ACCESS MEDICAL SCREENINGS AND TESTS

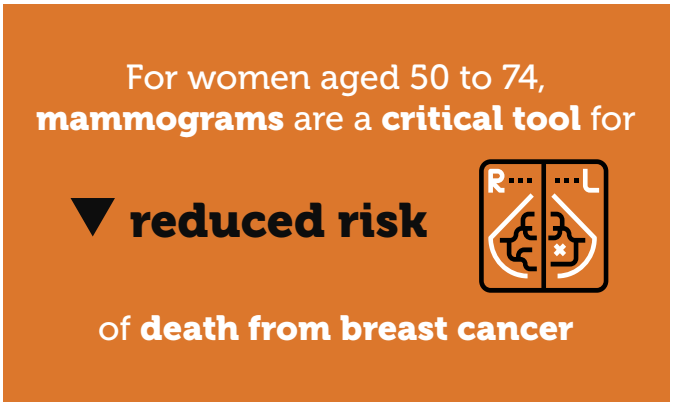
Benefits of Medical Screenings

Medical screening is the systematic application of tests to a particular population to identify the presence of an undiagnosed disease in individuals who do not presently exhibit signs or symptoms.[3] Screening is designed to identify diseases early in their development (or even before they have developed), enabling earlier intervention and disease management.

While screening tests can identify the presence of disease, they are not usually intended to be diagnostic.[4] Individuals with positive tests or results that strongly indicate the presence of disease typically require a verified diagnosis before beginning treatment.[5]

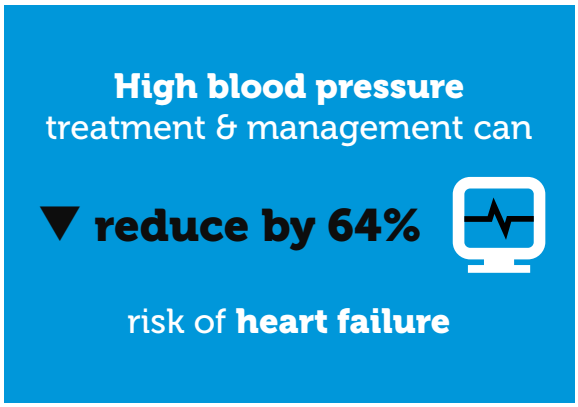
The benefits of any type of medical screening are, like genetic tests, tied to early diagnosis and treatment of diseases that severely jeopardize patient health and require extensive medical intervention to manage.

For example, mammography is effective at diagnosing breast cancer early. The USPSTF and American Academy of Family Physicians believe that mammography is an important tool to reduce the risk of dying from breast cancer for women aged 50 to 74 years.[6]



The USPSTF also recommends screening men 35 years and older and women 45 years and older for high blood levels of low-density lipoprotein (LDL) cholesterol, and recommends screening all adults 20 to 45 years of age if they have risk profiles that make them particularly susceptible to heart disease.[7] A corroborating study found substantial evidence that screening and treatment can significantly lower heart disease in people with abnormal lipid levels and could accrue additional lifetime quality-adjusted life years (QALYs) at an expense of only $48,500 per QALY for hypertension and $33,800 per QALY for high cholesterol, well below the $100,000 per QALY generally used to determine cost-effectiveness.[8]

Treatment can reduce the risk of incident stroke by 35% to 40%, of myocardial infarction (heart attack) by 15% to 25%, and of heart failure by up to 64%.[9] Moreover, medical researchers have found that screening for mild hypertension can extend quality-adjusted life years for patients subject to early interventions at very reasonable prices per QALY.[10] Results from studies in Canada showed hypertension screening resulted in 3 fewer hospitalizations per 1,000 patients.[11]



The National Lung Screening Trial (NLST) compared lung cancer screening with low-dose computed tomography (CT) scanning versus traditional chest radiography or no screening and found that, although CT scanning cost an additional $1,631 per patient versus no screening, it provided 0.0201 QALYs per person at a cost-effective rate of $81,000 per QALY.[12]

Denials and Other Barriers to Coverage

According to DPRP's 2017 survey, insurance companies deny 1 in 10 (10%) claims for medical testing or screening from patients treating a chronic or persistent illness or condition. One in every ten claims could represent as many as 7.7 million insured Americans treating a chronic disease, all of whom would face substantial cost barriers when trying to access the tests and screens their doctors believe could predict or identify potentially life-threatening conditions.[13]

"Medical Necessity" Most Common Justification for Denials

The most common justification insurers provide for denying coverage of a diagnostic or medical screening test is that the denied procedure is "not medically necessary" (28%).

Like medications, the prices for common preventive procedures can vary, even for insured patients.[14] For example, the average price for a double mastectomy to preemptively remove the breasts of patients at high-risk for breast cancer and reconstruct the breast can range anywhere from $15,000 to $50,000.[15]

Yet, while an insurer may question the necessity of a specific medication a doctor has prescribed to treat a particular condition without disagreeing with the medical necessity of the drug treatment itself, the same cannot be said for most preventive tests and prophylactic

interventions. Though there may be several different prophylactic procedures to prevent the development of a particular disease, physicians follow a standardized technique that does not vary by "brand," the way some medications do.

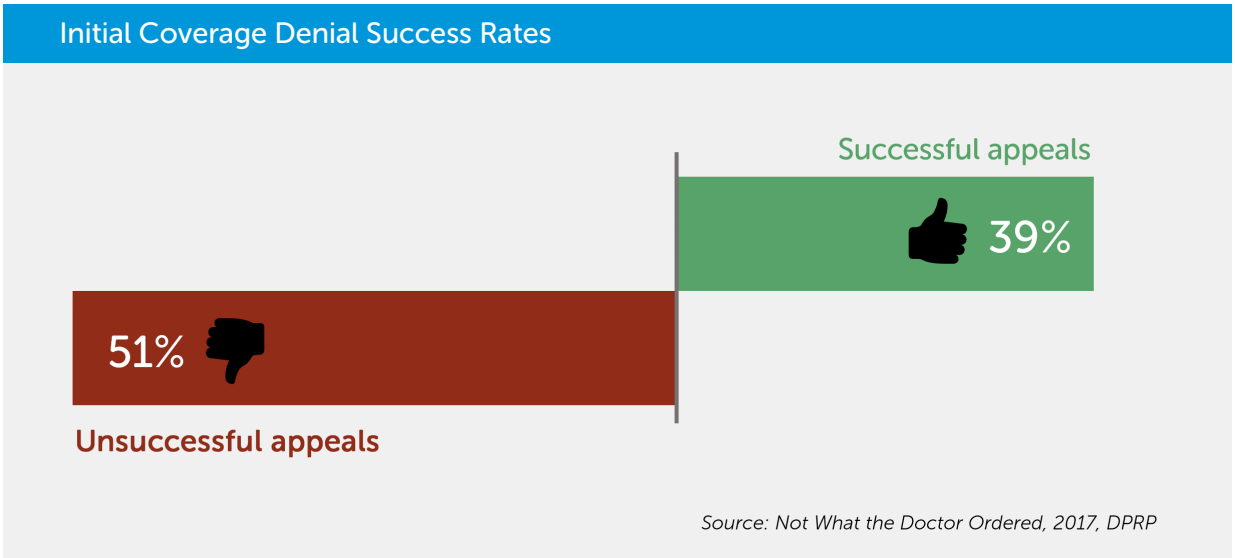
Surgeries to address breast cancer, for example, include simple (total) mastectomy, partial mastectomy (lumpectomy or quadrantectomy), and radical mastectomy.[16] Each is a different procedure for removing part or all of the breast, but it is recommended that each type of removal be performed in a similar manner by all surgical oncologists.[17]

Nevertheless, insurers are more likely to deny claims for prophylactic treatments by declaring that the requested preventive care is not medically necessary.[18]

Low Success Rate for Appeals

DPRP found that patients appealed about 40% of denied claims for prescribed tests or medical screening, compared to 42% of coverage denials for prescription medication claims.

Regardless of the type of claim, DPRP's survey revealed that all patients treating chronic or persistent illnesses or conditions have a low success rate attempting to overturn initial coverage denials. While 39% of patients who filed an appeal for denied tests or screens eventually won coverage from their insurance companies, more than half (51%) report that their appeal was unsuccessful.



The survey also found that just 14% of patients denied coverage of a diagnostic test or medical screening paid out-of-pocket for the prescribed service, versus 11% of patients denied coverage for a prescription medication. This suggests there are a number of patients who have claims denied, fail to successfully appeal that denial, and are unwilling or unable to pay out-of-pocket for their diagnostic or screening.

When coverage denials discourage patients from utilizing services, it can have a host of negative impacts on individual and public health. The following section looks at a number of common services, how insurers are denying coverage of each service and the benefits of those services that are lost through reduced utilization.

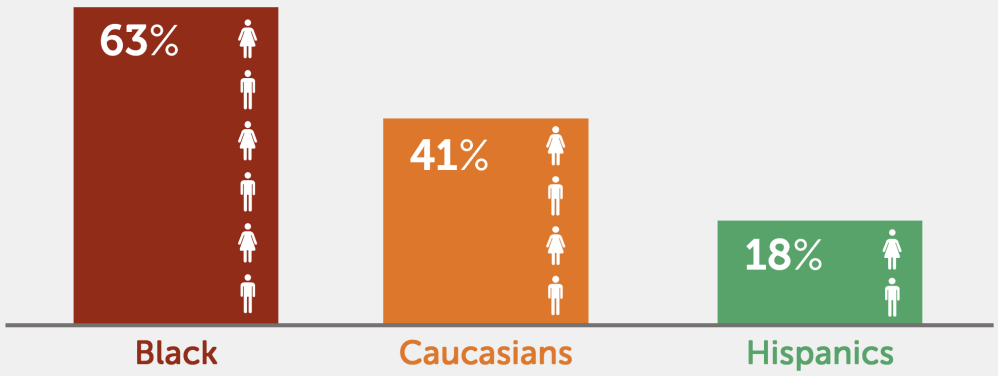
Younger & Urban Patients Denied Most; Significant Racial/Ethnic Disparities Exist

Younger and middle-aged patients seeking treatment for chronic conditions are more likely to have their claims for preventive care denied than older patients. Insurers agree to cover testing and screening for patients 50 years of age or older much more often than for younger patients.

While urban patients denied coverage for treatment of chronic illnesses are more likely (59%) than their rural counterparts (46%) to be denied coverage for a prescribed medication, DPRP's 2017 survey found the reverse is true for medical testing or screening. Results showed that rural patients who were denied coverage were more likely to have a medical test or screening denied (46%) than those living in urban settings (41%).

Black patients treating chronic or persistent illnesses who received coverage denials reported the highest rate of denials for diagnostic tests and screenings. According to the survey, insurance companies deny 63% of claims for diagnostic tests or screens submitted by Black respondents, compared to 41% of claims submitted by Caucasians and just 18% of claims submitted by Hispanic patients.

Black Patients Report Highest Denial Rates For Diagnostic Tests & Screenings



Source: Not What the Doctor Ordered, 2017, DPRP

All patients treating chronic or persistent illnesses do not equally experience the impact of higher out-of-pocket expenses for medical screenings. Analysis of a representative sample of U.S. adults found that race and socioeconomic status accounted for significant differences in the use of breast and colorectal cancer screening during the period of economic downturn

in 2008.[19] Patients with annual incomes of $50,000 or more, and those with healthcare coverage, had significantly higher odds of getting screened.[20]

Socioeconomic status has been found to account for much—but not all—of the disparity in patient utilization of various medical screening tests.[21] For several different diseases, race is the primary characteristic accounting for significant disparities in the utilization of medical screening as well as the morbidity and mortality of the diseases being screened.

High cost barriers are only one reason Caucasian patients are screened for colon cancer at twice the rate of Spanish-speaking Hispanics.[22] Black women are less likely to be screened for osteoporosis regardless of insurance coverage, net worth, age, geographical area, underlying health status, prior history of low bone mass or how often they utilize primary care.[23] Studies have also shown a direct correlation between woman who receive cervical cancer screening with increased education and income levels, and reported screenings were lowest among those who lacked health insurance.[24]

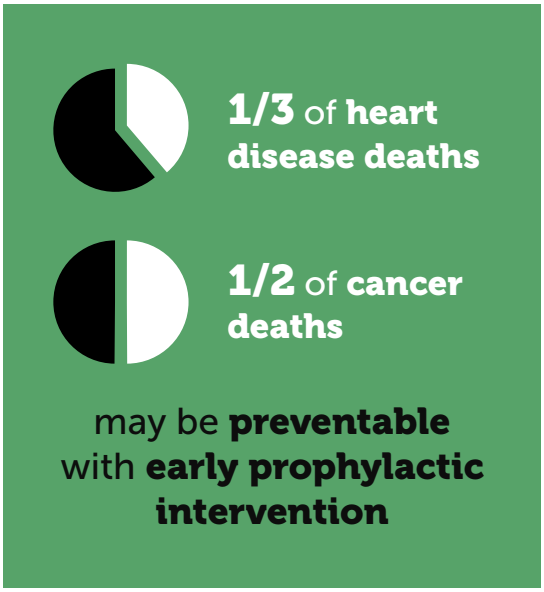
INSURERS CREATE BARRIERS TO ACCESS PROPHYLACTIC INTERVENTION

Benefits of Prophylactic Intervention

Around 25 of the 30 years of additional life expectancy Americans have gained in the last century are the result of prophylactic interventions, which are strategies that seek to avoid the development or slow the progression of a disease rather than treat or cure it.[25]

Preventable lifestyle choices—like smoking tobacco, poor diet and physical inactivity—account for just under 40% of all deaths in the U.S. annually.[26] One-third of all heart disease deaths and up to half of all cancer deaths are believed to be preventable with early prophylactic intervention.[27]

In some cases, genetic testing alone can predict with a high degree of accuracy the likelihood that a patient will or will not develop a disease.[28] Likewise, when sufficient evidence links environmental or lifestyle choices to a particular disease, screening alone can accurately identify patients at greater risk of developing the disease.[29]



Prophylactic intervention is expensive. A contralateral prophylactic mastectomy can cost between $66,000 and $87,000 on average.[30] Prophylactic treatment of hemophilia A with clotting-factor concentrates costs more than $100,000 a year on average.[31]

However, the cost of prophylactic intervention can be ameliorated by marrying preventive care to genetic testing and screening. Expensive interventions can generate substantial savings over other treatment options when they are targeted at the high-risk patients who are most likely to develop a preventable condition or who experience the most severe outcomes from development of a preventable disease.[32]

Several health policy analysts have questioned whether measuring the cost-savings of preventive care is a particularly useful exercise, when the fundamental goal of healthcare services is not to save money, but to extend life.[33] [34] [35] [36] Some policy analysts have suggested that a better measurement of the value of preventive interventions would entail looking less at the cost-effectiveness of preventing disease and more at the long-term value in promoting better patient health.[37]

The vast majority of prophylactic interventions, for example, fall below the $100,000 per QALY gained threshold typically used to determine whether investments in patient health are cost-effective, even if they do not generate cost-savings for insurers.[38]

Most **prophylactic interventions** fall below

$100k/QALY

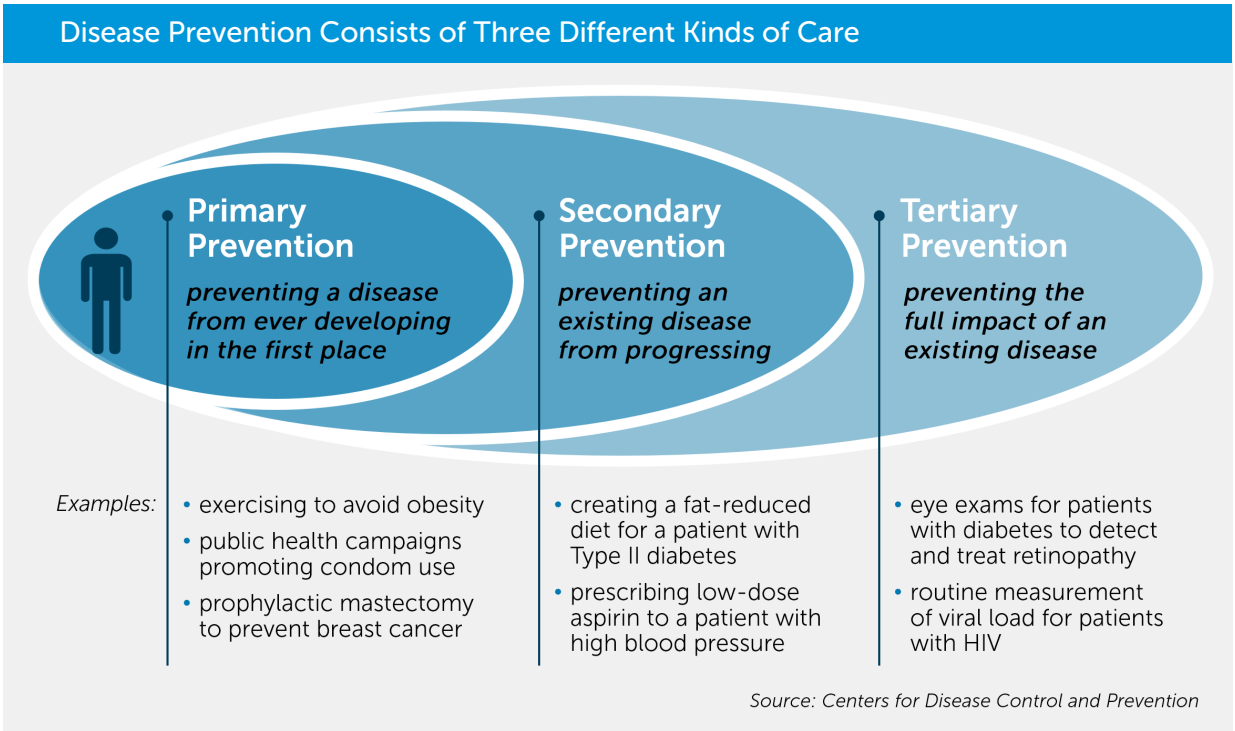
gained threshold used to determine **cost-effectiveness**

Denials and Other Barriers to Coverage

Cost Sharing Reduces Utilization of Prophylactic Interventions

Utilization of prophylactic intervention often hinges on insurance coverage. Patients with insurance are more likely than uninsured patients to utilize preventive care.[39] But even among patients with health insurance, cost-sharing burdens like copayments and deductibles can deter them from utilizing preventive services and prophylactic interventions.[40] This deterrent effect is evidenced in studies showing the ACA's elimination of cost-sharing for certain preventive services significantly increased their utilization.[41]

In practice, disease prevention consists of three different kinds of care, very little of which falls under the ACA provisions prohibiting insurers from imposing cost-sharing obligations.



Prophylactic intervention can fall into any of these categories, but is most often considered primary prevention, since it often involves medical procedures intended to forestall a condition in patients whose genetic testing or medical screening indicates are likely to develop a disease.[42]

In the absence of an explicit mandate under the ACA, private insurance coverage of prophylactic interventions may vary widely, even within health plans. To obtain coverage under most private insurance policies, patients must establish that the expense is "medically necessary" to address the condition and improve the policyholder's health.[43]

"Medical Necessity" Most Common Justification for Denials

Determining whether a prophylactic intervention is medically necessary is central to efforts to control healthcare costs in the U.S. and can be the primary obstacle to patients seeking coverage of preventive care.[44]

Even where the law would appear to require insurers to cover prophylactic interventions, insurers may deny coverage claims based on medical necessity. Under the Women's Health and Cancer Rights Act of 1998, for example, employer-sponsored and group health plans are required to pay for breast reconstruction surgery for women undergoing prophylactic mastectomy.[45] Nevertheless, some patient advocate groups claim insurers routinely deny requests for prophylactic mastectomy (as well as requests for breast reconstruction) on the

basis that neither is medically necessary, even when the requests come from women at high risk of developing breast cancer.[46]

Rather than the insurer having to justify denials based on medical necessity, patients have the burden of proving that the procedure they want covered is medically necessary.[47] Public outcry over the sheer number of insurer determinations, however, led to the inclusion of provisions in the ACA mandating external, third-party review of medical necessity determinations.[48]

External, third-party review has not always proven an effective, independent arbiter, however. For example, Aetna and BlueCross BlueShield of Delaware (BCBSD) contracted with MedSolutions, a Tennessee-based healthcare company, to review physician requests for cardio stress tests and advanced cardio imaging tests to determine whether they were "medically necessary."[49]

External reviews are intended to be independent. But, a U.S. Senate investigation discovered that MedSolutions marketing materials to Aetna and BCBSD guaranteed that it would significantly reduce the insurers' claims payments.[50] The investigation also revealed that the MedSolutions contract allowed the company to charge higher fees if it could save the insurers more than 20% in claims payments, a provision the Delaware Insurance Commissioner determined was in violation of the state's ban on "contingent savings" agreements between insurers and third parties.[51]

While Delaware and other states have taken steps intended to prevent remuneration agreements that erode the independence of third-party review, some insurers are circumventing regulations by inserting provisions into their policies providing patients with notice that their enrollment constitutes agreement to third-party review under the insurer's terms.[52] In Washington State, for example, such provisions have been held permissible by the state insurance commissioner if insurers provide notice to enrollees when they sign up.[53]

Barriers to Prophylactic Interventions Can Negate the Value of Screenings and Tests

Predictive tools like genetic testing and medical screening have limited clinical benefit if patients cannot access the prophylactic interventions necessary to address disease risk before a condition develops. For example, the highest incidence of HIV is among young men who have sex with men (MSMs).[54] Pre-exposure prophylaxis (PrEP) is highly effective at reducing the incidence of HIV among this cohort.[55] However, utilization of PrEP by MSMs remains low due to lack of access to covered healthcare.[56] One survey of 18-to-24-year-old MSMs found that only 3.4% had used PrEP and those that did not use PrEP cited lack of access to insurance coverage as the greatest single structural barrier.[57]

At close to $2,000 for a 30-day supply, the cost of PrEP is beyond what many patients can afford without an insurance company covering most of it.[58] Even when insurers cover the prophylactic intervention, some insurance companies have adopted utilization management strategies[59] or other barriers that prevent widespread access to PrEP among the groups most at risk of contracting HIV.[60]

Prophylactic Interventions Can Lead to Retroactive Coverage Denials for Preventive Screenings

With the exception of low-dose aspirin, specified vaccinations and smoking cessation aids, the list of standard preventive care for adults that the ACA requires health plans to fully cover consists entirely of screening and counseling services, with no mandate to cover actual preventive care.

Under the ACA's indirect coverage of preventive services, a patient who undergoes a colonoscopy and finds no evidence of colorectal cancer pays nothing for the service. If, however, the colonoscopy reveals pre-cancerous polyps, which the doctor removes and biopsies, the patient not only must pay relevant out-of-pocket fees on the polyp removal, but could also be on the hook for the cost of the colonoscopy (since, upon discovering evidence of cancer, the procedure turned from "preventive" to "diagnostic").[61] Thus, under a strict reading of the ACA, actions that prevent disease are not considered "preventive care," while actions that confirm the *absence* of disease are.[62]

INSURERS CREATE BARRIERS TO ACCESS GENETIC TESTING

Benefits of Genetic Testing

Genetic testing and services are somewhat new healthcare options, the result of groundbreaking advancements in genomics (the study of genetic material, like DNA) and genetics (the study of inherited characteristics encoded in that material). As biologists discovered that genes can carry abnormalities that cause a number of diseases, they surmised that identifying the variances in genetic material might be useful in predicting which patients are more likely to develop a particular heritable disease and developed tests analyzing human DNA, RNA and assorted chromosomes to detect these alterations.[63]

Today, there are just under 67,000 genetic tests available, covering almost 5,000 different disorders stemming from mutations in more than 5,900 different genetic sequences.[64]

67,000
genetic tests

5,000
disorders
from mutations in
+5,900
genetic sequences

Genetic tests can be used to determine a subset of patients likely to develop a heritable disease, rule out patients who are unlikely to develop the disease or help confirm a diagnosis when doctors suspect a patient might have a particular heritable condition.[65]

An obvious benefit of genetic testing is that it alerts patients and their doctors to the likelihood that a patient will develop a heritable disease and may compel doctors to more closely monitor patients who do not presently show symptoms. This extra scrutiny facilitates early diagnosis and treatment, which can prevent negative medical outcomes from happening in the future.[66]

Genetic testing can also facilitate care that improves patient health. Although gene mutations account for only 5% to 10% of colorectal cancer, individuals carrying the mutation have a 70% lifetime risk of developing the cancer.[67] Monitoring these individuals through regular colonoscopies can reduce colorectal cancer development by up to 62% and substantially improve the outlook for patients.[68]

Chronic diseases already account for 75% of all healthcare costs in the United States. They are generally incurable, affect 40% of the population[69] and they only get worse as the patient gets older. But they can be prevented if patients take actions before the disease becomes more severe, such as eating healthy meals and participating in physical activity.[70]

Genetic testing can have unexpected benefits for patients as well. If a genetic test involves genome sequencing, the test protocols can reveal mutations that may not have been the target of the testing—nor even considered by the patient's physician.[71] Being alerted to these mutations could prove beneficial for early intervention or in determining the best treatment options before symptoms of a completely unrelated condition arise.[72]

The potential savings genetic testing achieves by avoiding treatment of heritable diseases are often greater than the combined cost of genetic testing, disease surveillance and prophylactic intervention combined. For example, traditional management of hypertrophic cardiomyopathy (HCM) involves periodic screenings throughout a patient's lifetime, which can add substantial costs to a patient's lifetime care.[73] A 2012 study by Australian researchers evaluated the cost-effectiveness of genetic testing of family members suspected of carrying the gene variant for HCM compared to the cost of treating the disease as it arose in family members not tested.[74] The study found that, while genetic testing added additional expenses, it substantially extended the lives of patients by facilitating early intervention, and did so at a very reasonable price.[75]

Denials and Other Barriers to Coverage

Loopholes in Coverage Requirements Allow for Inconsistency in Denials

Insurance coverage of genetic testing traditionally has been limited by the fragmented nature of the private insurance market.[76] Coverage for genetic testing improved somewhat after Congress passed the ACA, which established a set of "Essential Health Benefits" (EHBs) that must be covered by individual and small group insurers without charging patients a copay, particularly for patients with lower education and income, as well as groups that previously faced the highest cost barriers to screening.[77] For example, because of EHB provisions, patients who switched insurance to a high-deductible health plan after the ACA eliminated cost-sharing for screening increased their utilization rates for both colorectal cancer screening and screening colonoscopies.[78]

Despite these improvements, however, a number of issues continue to create barriers for patients trying to access genetic testing services – including health plans being exempted from the ACA requirements, idiosyncrasies in USPSTF recommendations, and complexities involved in determining the actual intent of preventive services.[79]

Further complicating matters, individual insurers employ different definitions for whether a preventive test or service is predictive, diagnostic or therapeutic. For example, while the ACA mandates coverage of preventive services like predictive mammograms, it does not mandate that insurers provide free diagnostic services.[80] Consider a woman with breast cancer in remission who sees her doctor for an annual mammogram. While she might view the procedure as purely preventive, her doctor may code it as diagnostic, thinking the testing or service is necessary to prevent a reoccurrence of the cancer. This difference in perspectives becomes a major factor when insurance companies determine whether to cover the procedure.[81]

EHB benchmark plans present another challenge. Insurance plans sold in ACA state exchanges are required to cover 10 essential health benefit categories and mirror the benefits provided by a benchmark plan chosen by the state.[82] While exchange benchmark plans provide a potential mechanism for states to compel more consistent coverage of genetic testing and services, they can often limit coverage of genetic testing and create greater interstate variability in coverage as well.[83] Iowa's benchmark plan, for example, explicitly excludes coverage of genetic tests intended for informational purposes, while Maine's will only cover genetic testing and counseling if it uncovers information that directly impacts the determination of a treatment plan.[84]

Quality of Life Years an Inadequate Measure of Cost-Effectiveness

Quality Adjusted Life Years

Health economists often express the cost-effectiveness of care in terms of the number of quality-adjusted life years (QALYs) it saves.[85] QALYs are a measure of both the length and quality of life. Thus, one year of life in perfect health is equal to one QALY, while one year of adverse health would be worth between 0 and 1 QALY, depending on how much the adverse condition impacted a patient's quality of life.[86] Typically, the cost-effectiveness of a medical intervention is considered favorable if it "costs" less than $100,000 for each QALY gained, and unfavorable if each QALY gained by the intervention "costs" more than $100,000.[87]

Whether genetic testing is cost-effective depends highly on how it is targeted. For example, for patients with Lynch Syndrome—a heritable condition that accounts for up to 4% of colon cancers and up to 5% of endometrial cancers—current U.S. clinical guidelines call for genetic testing only after patients have presented with malignancies that a doctor finds "clinically suspicious" to determine how a patient will respond to various drug treatments.[88] As a result, though physicians are capable of using genetic testing to anticipate Lynch Syndrome before patients exhibit symptoms, in practice, the clinical guidelines can limit access to early detection and in some cases permit the deadly disease to develop.[89]

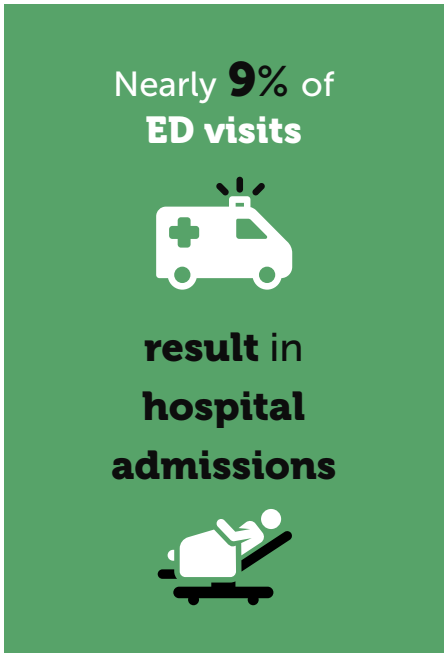
EMERGENCY CARE

INSURERS CREATE BARRIERS TO ACCESS EMERGENCY CARE

Benefits of Emergency Care

Each year, nearly 137 million visits to the emergency room are made in the United States.[90] During a one-year period, approximately one in five people reported visiting an emergency room for some form of medical care.[91]

Nearly 9% of ED visits resulted in patients being admitted to the hospital; just over 1% of ED visits result in patients being admitted to the critical care unit; and more than 2% of patients seen in the emergency department are transferred to a different hospital, such as a psychiatric hospital.[92] In 2015, the most common symptoms cited by patients seeking care in emergency departments were abdominal or stomach pain, chest pain, and fever.[93] As the U.S has seen an increase in opioid misuse, emergency rooms are also seeing a spike in cases for individuals with substance abuse disorders.[94] In a 2017 study by the University of Maryland School of Medicine, findings revealed that nearly half of medical care in the United States originates in emergency rooms, with women and minorities showing higher occurrence rates.[95]



The majority of emergency room patients are between the ages of 18 to 44 (38% in rural settings and over 40% in non-rural settings), followed by pediatric patients (22% in rural locations and 21% in non-rural locations), patients aged 45 to 64 (21% for both rural and non-rural settings) and patients 65 and older (19% in rural settings and 17% in non-rural settings).[96] White patients have the highest occurrence of emergency room visits, followed by Blacks, Hispanics and Asian and Pacific Islanders.[97]

Patients visiting the emergency room are predominately covered by private insurance, followed by Medicaid, and then uninsured individuals.

Denials and Other Barriers to Coverage

Denying Coverage for "Avoidable" Visits

Under federal law, insurance companies cannot deny coverage if a "prudent layperson" would believe that they required emergency care and services. However, such an ambiguous standard has created an intricate web of state regulations that have allowed insurance companies to implement policies that flout the intent of the law.

Insurance companies have been exploiting the ambiguity in federal law by retroactively denying claims based on whether or not such claims were "avoidable." For example, during the second half of 2017, Anthem BlueCross / BlueShield denied more than 12,000 claims from patients in Missouri, Kentucky and Georgia on the grounds that their visits to the emergency room were "avoidable."[98] [99] Those denials are equivalent to approximately 5.8% of all ER claims submitted from those states during that period.[100]

In contrast, a study published in *International Journal for Quality in Health Care* of 424 million ED visits made by patients between 2005 and 2011 found that only 3.3% of those visits fit a conservatively-defined standard of being "avoidable."[101] Furthermore, a significant number of these "avoidable" visits were related to areas of care that most EDs are not fully equipped to treat, such as mental health and dental conditions.[102] Even for non-urgent ED visits initially triaged as non-urgent when the patient first presented, many underwent a diagnostic imaging test that ended with a notable proportion of them being admitted to the hospital—sometimes to a critical care setting.[103]

In addition, many patients seeking emergency care believe that they are receiving care accepted by their insurance company, only to be presented with an unexpected bill for tens-of-thousands of dollars because the hospital or specialist was out of network or because their insurance plan had a high deductible they had to first pay out of pocket before their care was covered. One study found that 14% of patients treated in the ER but not admitted to the hospital for additional care end up with this type of out-of-network bill. When a patient was admitted for additional treatment that number went up to 20%.[104]

Retroactive Denials for Emergency Care

The 12,000 emergency care claims denied by Anthem resulted from a new policy the company adopted in certain states effectively denying coverage if the insurer retroactively determined that the patient did not have a condition requiring emergency care.[105] [106]

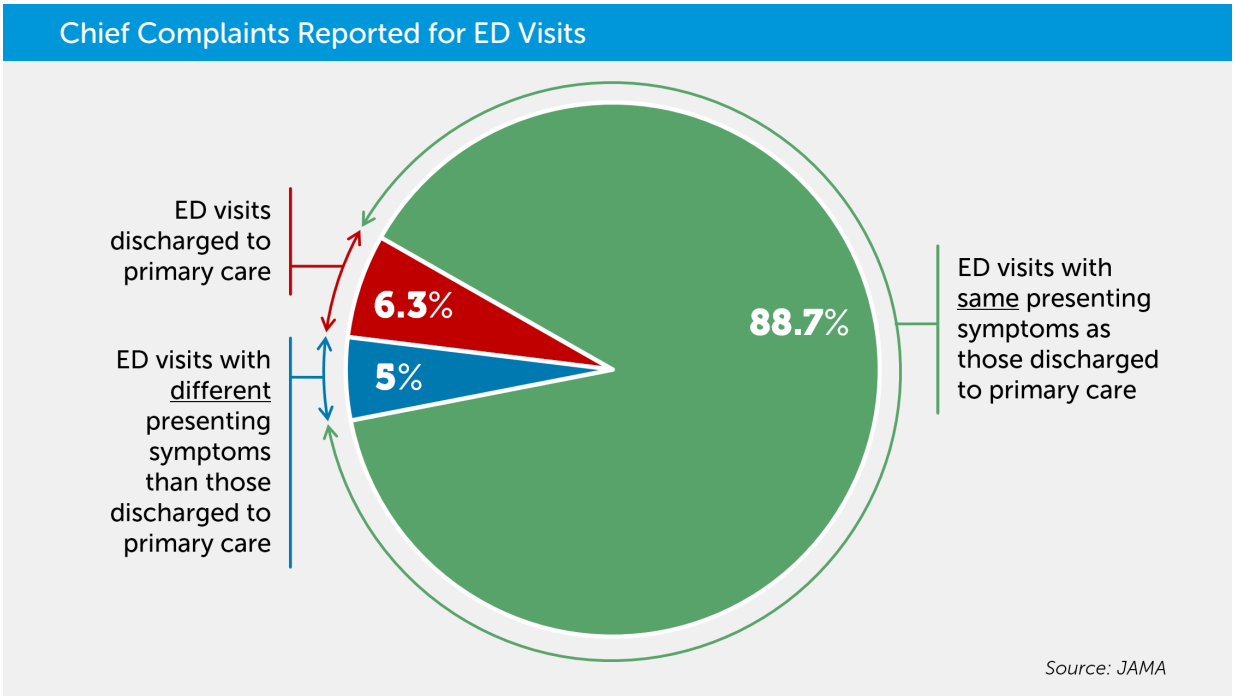
Anthem initially rolled out this policy in three states—Missouri, Kentucky and Georgia—but as of August 2018 had expanded the number of states to include Indiana, Ohio, and New Hampshire.[107] [108] [109] One woman in Kentucky, who went to the emergency room with

severe abdominal pain thinking her appendix burst, had Anthem determine her ED visit was unwarranted because upon examination the source of her pain turned out to be ovarian cysts.[110]

While the insurance industry has relied on a list of nearly 2,000 diagnoses in Missouri that are considered "non-urgent" and "non-reimbursed" to determine whether or not they should pay a claim, they used shorter lists in other states and such lists do not fully reflect how these diagnoses could, in fact, be symptoms generated by conditions that *do* require emergency care. For example, "chest pain on breathing" can be the result of several non-urgent conditions—or it could be the symptom of a life-threatening pulmonary embolism.[111] Anthem and other insurers also use a research tool developed by Professor John Billings of New York University's Wagner School of Public Health to determine if an emergency room visit was "avoidable," which the Professor says it was never intended to be used for.[112]

It is virtually impossible to differentiate emergent and nonemergent conditions based on presenting symptoms. A study in the *Journals of the American Medical Association* looked at presenting complaints and discharge diagnoses for nearly 35,000 ED visits.[113] The study found that the chief complaints reported for the 6.3% of ED visits that resulted in a primary care-treatable discharge diagnosis were the same chief complaints reported for 88.7% of all ED visits.

Of these 88.7% of visits, 11.1% needed immediate or emergency care; 12.5% required hospital admission; and 3.4% of admitted patients went directly from the ED to the operating room.[114] This indicates that relying only on a diagnosis code is not an effective approach to ensuring patients sought care appropriately.



In many instances, insurer denials for emergency care end up being overturned. In California, for example, a 2016 study conducted by the *California Department of Managed Health Care* and the *California Nurses Association* found 52% of emergency care claims denied by insurers were overturned or reversed after independent review.[115]

Other analyses have demonstrated how difficult it can be to determine what ED visits should be considered appropriate or inappropriate. A study published by the *National Center for Biotechnology Information* looked at seven indicators of "inappropriate" ED visits: two that could be determined by the patient, two by a triage nurse and three by retrospective chart review. The proportion of visits that an individual indicator found to be inappropriate ranged from 10% to 90%, emphasizing that the criteria used determine appropriateness has a tremendous impact on whether an individual visit is found to be appropriate.[116]

Deterring Avoidable Visits Unlikely to Relieve Burden on Healthcare System

Despite the insurance industry's claims that ED visits can be more effectively handled by a Primary Care Provider (PCP), a study from the *Society for Academic Emergency Medicine* found that up to 32% of non-urgent ED patients said lack of access prevented them from seeking care from a PCP.[117] These findings suggest that healthcare services are needed even for the lowest acuity visit and calls into question the designation of a non-urgent ED visits as being "avoidable."

Many PCPs are finding it difficult to care for patients because of coverage denials and prior authorization requirements for the care they provide, which contributes to an increase in referrals to EDs. A 2013 RAND report noted that EDs are being used more frequently by primary care physicians for an accelerated diagnosis of a patients.[118]

There is also no guarantee that discouraging patients with non-urgent symptoms from visiting an ED will have any significant impact on overcrowding. In a recent report on ED utilization and capacity, the Robert Wood Johnson Foundation found that "care provided to the uninsured and patients with non-urgent conditions is not a driver of ED over-crowding."[119] Instead these policies can themselves create additional obstacles to patients seeking needed care or impose costly burdens on those who receive care.

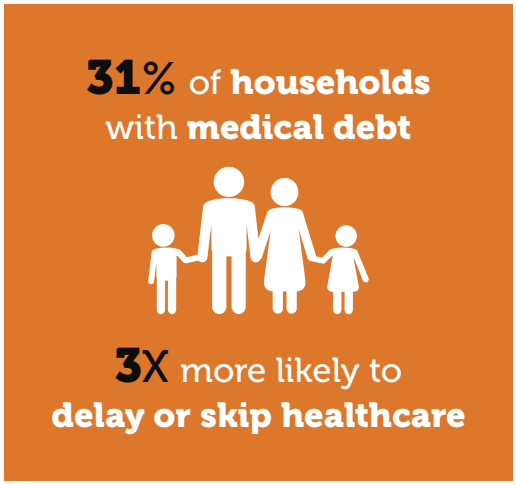
The increase of admitted patients is one of many factors contributing to high demands and wait times for EDs. Other factors include aging populations, an increase in the complexity of diagnostic evaluations and treatments taking place in the ED, along with the growing pressure to shift care away from the inpatient setting.[120] Insurers have leveraged these wait

times and crowding issues as justification to institute policies they say are intended to deter the use of EDs for non-emergency care.

Financial Burdens Create Obstacles to Additional Care and Put Strain on Hospitals

Emergency care denials saddle patients with medical debt that can prove financially devastating and can ultimately deter them from seeking care for other health issues.

A 2016 Kaiser Family Foundation survey found that 31% of households with medical debt failed to properly treat other health problems as a result and families with medical debt are up to three-times more likely to have delayed or skipped healthcare than families without medical debt.[121]



The problem of medical debt does not just impact patients; it can contribute to financial burdens for hospitals themselves. Hospitals and other healthcare providers write off tens-of-billions of dollars in bad debt every year, largely the result of unpaid medical bills.[122] [123]

This presents many EDs with a difficult choice: absorb the costs of unpaid bills, increasing the risk of financial insolvency, or adopt more aggressive tactics to pursue patients who have not paid their bills.

CONCLUSION

Medical insurers are blurring the lines between doctor and insurer by effectively choosing which procedures are available for patients seeking preventive and emergency care.

Medical screenings allow patients to proactively receive information about conditions, so they can take preemptive action and potentially eliminate the need for costly medical treatment. Yet according to our survey, one in ten claims are denied by insurers, most often claiming the screening was not medically necessary. This can discourage early detection, putting more of a burden on emergency departments and the health care system as a whole.

Even in instances where patients are able to access screenings or genetic testing, they are often prevented from utilizing prophylactic interventions to prolong or improve quality of life. And by choosing to employ such interventions, patients may retroactively reclassify a preventive screening as diagnostic, throwing the coverage of that procedure into question.

Additionally, as the number of emergency visits in America continue to rise, insurers are denying coverage for patients considered to be "avoidable," even when prescribed by a primary care provider or when symptoms could have reasonably indicated a life-threatening condition. As insurers expand these retroactive denials, it can discourage patients from seeking care and place a high financial burden on both patients and hospitals. While insurers argue that denials are necessary to manage overall healthcare costs, research suggests that covering preventive services upfront could actually save the system money in the long term.

Based on the full analysis in both *Access Denied* reports, the Doctor Patient Rights Project finds patients are being impacted by denials at every phase of care—preventive, and emergency medical treatment.

This is a problem that effects patients across demographics, but as is so often the case, impacts high-needs populations the most. It is a problem that must be addressed to truly empower patients and their doctors to make decisions about their care.

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The Doctor-Patient Rights Project is a non-profit coalition of doctors, patients, caregivers, companies and advocates fighting to restore the fundamental practice of medicine and to ensure doctors, in partnership with their patients, drive patient care decisions.

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