Pillars of Health Care Reform

By. National Patient Advocate Foundation

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Our current health care system is unsustainable. Expanding uninsured rolls, escalating health care costs, and "bare bones" benefit packages are impacting the personal and financial healths of millions of Americans. ***National Patient Advocate Foundation strongly supports a national solution aimed to expand access to health coverage while reigning in costs and spending.*** Health care reform must transform our health care system to an equitable, patient-centric system that promotes quality care through health information technology, prevention and disease management while encouraging individual accountability.

National Patient Advocate Foundation believes that a responsible health care system is based upon the following principles: **universal, affordable, quality, fair & equitable, and portable.** Our pillars of health care reform have been informed through the experience of the patients served through our companion organization, Patient Advocate Foundation (PAF) which provides counseling and case management services to patients throughout the country. Last year, Patient Advocate Foundation received more than 7.5 million contacts from patients throughout the United States seeking information and assistance for access to care issues resulting from diagnoses of a chronic, debilitating or life-threatening disease. Of those, 45,870 became full patient cases involving communications made by PAF staff on behalf of a patient in order to reach positive resolution. The experience of the patients served by Patient Advocate Foundation helps illustrate the problems and deficiencies in our health care system.

Universal

The latest data available supports that 47 million Americans, approximately 16 percent of the population, were uninsured in 2005.[1] Even more alarming is that almost 90 million Americans (about one-third of the under age 65 population) spent a part of 2006 or 2007 without health insurance coverage.[2] The situation continues to get worse year after year. From 2005 to 2006, the number of uninsured Americans increased 2.2 million; since 2000 the number has increased almost 9 million.[3] Working age adults were at the center of the increase in the number of uninsured Americans in 2006; approximately 1.3 million full-time workers lost their health coverage that year.[4] At the same time patients are finding it increasingly difficult to bare the burden of increased cost-shifting, employers are being forced to drop coverage due to mounting health care costs; the result is a sense of instability in our health care system. Between 2003 and 2007, access to care deteriorated for many patients, particularly low-income children and people with the greatest health care needs.[5]

Every American needs and deserves access to health coverage. NPAF supports a multi-faceted health care system that includes and supports the role of individuals and other stakeholders including: government, business, providers, and charitable organizations. Every patient seeking assistance from Patient Advocate Foundation has complicated health and

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[1] DeNavas-Walk, C.B. Proctor, and J. Smith. Income, Poverty, and Health Insurance Coverage in the United States: 2006. U.S. Census Bureau., August 2007.
[2] Families USA. Wrong Direction: One Out of Three Americans are Uninsured. September 2007.
[3] DeNavas-Walk, C.B. Proctor, and J. Smith. Income, Poverty, and Health Insurance Coverage in the United States: 2006. U.S. Census Bureau., August 2007.
[4] Families USA. Wrong Direction: One Out of Three Americans are Uninsured. September 2007.
[5] Center for Studying Health System Change. Falling Behind: Americans' Access to Medical Care Deteriorates. June 2008.

insurance problems. Day after day and week after week, PAF case managers assist patients fighting to gain and/or maintain health coverage, struggling to resolve reimbursement and billing problems, and wrestling with medical debt crisis and job retention issues.

Several months ago, Patient Advocate Foundation was contacted by a 20-year old woman who was diagnosed with a cardiac condition/tachycardia as a child. Not long after she aged off her parents health insurance policy at age 19, she got married and had a child. When her husband attempted to add his family onto his insurance policy, he was told they would not cover his wife due to her health history. The patient then attempted to acquire coverage through the high-risk pool in her state of Florida; however, she was informed the Florida risk pool had not accepted any new patients since 1991 mainly due to lack of funding. The patient explored coverage options in the private individual market, but the $1080 per month in premiums she was quoted was not financially feasible for her and her family.

A misconception exists in our country that anybody can get health insurance in the United States. Almost 15 percent of the population does not have employer sponsored health coverage available to them, either through their own employer or spouses'.[6] The reality is that beyond employer-sponsored health coverage, there are few options for individuals and families to gain health coverage. Health coverage options exist for some of our most low-income citizens, and individuals with financial resources also have the ability to afford coverage; it is the middle class that find themselves unqualified for state and federal assistance programs and unable to afford coverage in the private individual market.

Last year a 37-year old self-employed man contacted Patient Advocate Foundation. He had previously been diagnosed with Noonan's Syndrome (congenital heart malformation) and Congestive Heart Failure. After exploring insurance options on his own, he contacted PAF because he had hit a wall. He could not find insurance coverage due to his current health status and his health history. In the meantime, the patient was receiving full charity care at his local hospital and was also receiving medication assistance. Patient Advocate Foundation was able to help him enroll in federal assistance programs at exactly the right time – soon after he underwent a heart transplant. Without his acceptance into these programs, he might not have been able to access the much needed care. While public assistance was available to this patient because of his limited assets, Patient Advocate Foundation must regretfully inform many patients that these programs are not available to them; thus limiting their access to necessary health care services or resulting in no access at all.

Affordable

A growing number of individuals and families are finding that they cannot afford health coverage. According to The Kaiser Family Foundation, the average annual total premium cost for single coverage is $4,479; compared to $12,106 for family coverage.[7] As the employee share for health coverage rises – approximately 30% from 2001 to 2005 – employee

[6] Clemens-Cope, Lisa, et al, Changes in Employees' Health Insurance Coverage, 2001-2005, Kaiser Commission on Medicaid and the Uninsured, October 2006.
[7] Employer Health Benefits: 2007 Annual Survey. The Kaiser Family Foundation and Health Research and Educational Trust. September 2007.

wages have only increased 3% in the same time period.[8] Insurers and employers are shifting health care costs to patients; out-of-pocket health care spending has increased 115 percent since 2000.[9] Rising premiums and patient cost-sharing impact patients across the economic spectrum. Almost 40 percent of the uninsured population has annual household incomes greater than $50,000;[10] however, when family coverage costs over $12,000 per year, many families find themselves in an unfavorable position when trying to afford health insurance. This helps illustrate the financial strain that many in the middle class face when it comes to being able to afford health coverage for themselves and their families.

There are many misconceptions about why individuals go without health insurance coverage. While some argue that people *choose* to be uninsured, the experience at Patient Advocate Foundation tells us that the majority of individuals are unable to afford the cost of health coverage. For 70 percent of PAF cases, medical debt crisis was their first concern in 2007 representing a dramatic increase from the 28 percent of patients with debt crisis issues in 2004, and 38% in 2005 and 2006.[11] Nationally, 50 percent of all bankruptcies are related to medical debt and the majority of these patients had health insurance coverage at the onset of their illness or injury that lead to their financial issues.[12]

Coverage should be available that is affordable for individuals, families, businesses and government. More Americans find themselves uninsured every year because they cannot afford coverage and/or their employers cannot afford to offer coverage. Increased premiums, deductibles, and co-pays have led to high out-of-pocket spending for many patients. As costs are shifted to individuals and families, more Americans find themselves unable to afford coverage. Small businesses need assistance too so they can offer affordable coverage to their employees without facing financial ruin.

According to a recent report by the Center for Studying Health System Change, approximately 20% of the population has delayed or forgone necessary medical care in the last year, compared to 13% in 2003. Among those surveyed, 69% cited cost as their main reason for delaying care.[13] The reality is that the U.S. continues to spend more money every year on health care and patients increasingly delay or forego care; ultimately leading to worse health for patients and added cost to the system.

Rising health care costs make the affordability of health coverage an issue for many Americans. In December 2006, a 50-year old man was diagnosed with laryngeal cancer and contacted Patient Advocate Foundation. The patient was uninsured and working as a bulldozer driver for a construction company that did not offer health insurance to its employees. The man underwent treatment in early-2007 but exhausted all resources since he

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[8] State Health Access Data Assistance Center, University of Minnesota. Squeezed: How Costs for Insuring Families are Outpacing Income. April 2008.
[9] Hewitt Associates LLC. Health Care Expectations: Future Strategy and Direction 2005. November 2004.
[10] DeNavas-Walk, C.B. Proctor, and J. Smith. Income, Poverty, and Health Insurance Coverage in the United States: 2006. U.S. Census Bureau., August 2007.
[11] Patient Data Analysis Report For 2007. Patient Advocate Foundation. February 2008.
[12]Himmelstein, D.U., Warren, Elizabeth, Thorne, Deborah, and Woolhandler, Steffie. Harvard's Marketwatch: Illness and Injury As Contributors to Bankruptcy, February 2005.
[13] Cunningham, Peter, and Felland, Laurie. Falling Behind: Americans' Access to Medical Care Deteriorates, 2003-2007. Center for Studying Health System Change. June 2008.

was no longer able to work due to his disease. Soon after, a second cancerous nodule was discovered by his doctor and a preliminary scan, costing $800 was recommended. Even after receiving financial assistance from his family and former boss, the patient still could not afford a second opinion or the recommended care he was told he needed.

Seventy-three percent of the patients that contact PAF have some form of insurance coverage; however, for patients with a chronic or life-threatening disease, health coverage can still lead to major problems with medical debt particularly if they are one of the 25 million individuals in the United States that are classified as "underinsured".[14] According to a June 2008 study published in *Health Affairs*, "the number of adults who have health coverage that does not adequately protect them from high medical expenses" is up 60 percent from 2003. The majority of the "underinsured" are middle class Americans that have coverage they can afford until they get sick as it is only when they are faced with significant cost-sharing burdens in the form of copays, deductibles, and coinsurance or when they reach a cap on their benefits that they find themselves virtually uninsured. Part of the problem for the underinsured is how health benefits packages are designed by insurance companies (this issue will be discussed in greater detail in the following section). The expansion of cost-sharing responsibilities on the patient is one of the primary reasons that insured individuals contact PAF for access to health care problems.

After receiving a liver transplant in January 2008, a 32-year old patient contacted Patient Advocate Foundation because the insurance coverage she had through her husband's employer offered a maximum of $10,000 in prescription drug coverage per year. She reached this max half-way through the year and discovered that the cost for her anti-rejection medications would cost $2,000 per month. Because her husband earned a decent salary, she was not eligible for Patient Assistance Programs which would have provided some financial relief with her prescription drug costs. This patient has been unable to find any assistance for the financial burden she now faces. For her and patients in similar situations, there comes a point when decisions must be made about paying the bills and putting food on the table, or paying for prescriptions and medical care. For more and more Americans, this is a reality they know too well.

Quality

Even though the United States spends more money on health care than any other industrialized country, there is significant evidence that the quality of medical care trails other developed nations. Systemic problems exist that contribute to the poor quality of our medical care, especially since our system pays for good and bad care the same. Our current system proves that obtaining affordable health coverage does not guarantee that the care you receive will be high quality. In 2006, a study by The Commonwealth Fund found that one-third of patients reported a medical, medication or laboratory error during the previous two years.[15] These errors result in nearly 100,000 unnecessary deaths annually.[16]

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[14] Schoen, C, Collines, S.R., Kriss, J.L., Doty, M.M, How Many Are Underinsured? Trends Among U.S. Adults, 2003 and 2007, Health Affairs Web Exclusive, June 10, 2008 w298-2309.

[15] The Commonwealth Fund Commission on a High Performance Health System, Why Not the Best? Results from a National Scorecard on U.S. Health System Performance, The Commonwealth Fund, September 2006.

[16] Corrigan, J.; L. Kohn, M. Donaldson, eds. To Err is Human: Building a Safer Health System. Committee on Quality of Health Care in America, Institute of Medicine, The National Academies Press, 1999.

In addition to the direct costs medical errors create, the total national costs lost as a result of preventable adverse events, including lost income, lost household functioning, disability etc, are estimated to be $35 billion a year.[17] In terms of quality of care health measures, the United States ranks last when compared with six other developed nations and fails to attain enhanced health outcomes.[18]

NPAF supports the premise that every American should have timely access to quality coverage including a minimum standard set of benefits; the healthcare system should incent quality and promote transparency to encourage patients to be better purchasers of health care. The use of quality measures, comparative effectiveness research, and evidence-based medicine are tools that should be utilized to help improve the level of quality Americans receive in our health care system. A high-quality health care system needs to promote high-quality health care services and ensure patient safety.

Health coverage is not meaningful unless the coverage you have is high-quality and covers necessary health care services. A 50-year old man contacted Patient Advocate Foundation last year after being diagnosed with pancreatic cancer. His health insurance had a $1,000 cap on prescription drugs per year and $10,000 cap on any type of cancer treatment per year. His medical bills exceeded $65,000 when he contacted PAF, and with only his wife's annual salary of $50,000, the financial burden was too great for them to bear. A responsible health care system does not allow bare bones insurance policies to pass as adequate health coverage. Patients need protections from this type of coverage that misleads them into thinking they will be taken care of if they get sick.

Quality health care coverage leads to improved outcomes and better coordinated care for patients. One tool that has proven valuable to patients and providers is health information technology. The parents of a 13-year old patient sought the assistance of Patient Advocate Foundation after their daughter began experiencing severe headaches that caused extreme pain and vomiting. After her pediatrician ordered x-rays and other tests, only a slight area of concern was noticed by the radiologist. The family remained concerned however and after being provided a disc which contained all of the tests performed as well as radiology reports, the parents made an appointment with a pediatric neurologist. The neurologist and a pediatric radiologist onsite who specializes in neurological disorders were able to view the patient's electronic medical records and all of the tests included on the disc thoroughly and diagnosed the girl with Chiari Malformation. An appointment was able to be scheduled in very short order due to the immediate availability of the patient's health record in an electronic format.

Health information technology used in physician offices and hospitals has led to improved and timely diagnoses and helped reduce duplicative and unnecessary testing. Health care reform will not be successful if its only goal is to provide affordable health coverage to all Americans. Quality, high-value health care needs to be a prominent focus as we work to transform our health care system. In addition, while insurers and proponents of 'bare bones'

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[17] Corrigan, J.; L. Kohn, M. Donaldson, eds. To Err is Human: Building a Safer Health System. Committee on Quality of Health Care in America, Institute of Medicine, The National Academies Press, 1999.
[18] The Commonwealth Fund. Toward Higher-Performance Health Systems: Adults' Health Care Experiences in Seven Countries, 2007. November 2007.

insurance policies state these plans will help millions of uninsured Americans afford health care coverage, it's obvious patients are enrolling in health plans with little understanding that the coverage will not protect them if they get sick with anything more than the common cold.[19] Individuals enrolled in these insurance products may further erode the employer-based system as costs are shifted to hospitals and other struggling entities including but not limited to small physician practice groups.

Fair and Equitable

No person should be discriminated against due to health status. Under our current system, individuals are denied coverage, experience waiting periods for treatment, face exorbitant premiums and may have their health insurance policy rescinded when they need coverage the most. A responsible health care system must be unbiased while providing necessary coverage to those who need it when they need it.

Approximately 133 million Americans, or 45% of the population, has at least one chronic disease.[20] All of these individuals are at risk of facing health insurance discrimination due to their health status. Our current system treats individuals with pre-existing conditions differently than healthy Americans. For these individuals, they are at risk of facing long pre-existing condition waiting periods or worse, they may not receive coverage at all for their pre-existing conditions in the individual health insurance market. While some chronic diseases can be prevented and NPAF encourages individuals to take responsibility for their health, the majority of the patients served by Patient Advocate Foundation have a cancer diagnosis – 78% in 2007. These patients may be able to take steps to reduce their chances of being diagnosed with cancer, but for most, no amount of prevention and healthy behavior will stop this disease.

A common assumption exists that patients with pre-existing medical conditions can get health insurance coverage through their state high-risk pool. Unfortunately, for many patients, their state does not operate a high-risk pool since currently only 34 states have operational risk pools. In states with established high-risk pools, patients often face long waiting lists due to funding constraints and most frequently, patients are still faced with waiting periods for their pre-existing conditions. Since patients accepted into high risk pools are by nature "high risk", they face premiums in the pool that average 125 to 200 percent of the average, standard market rate for private health insurance; making high risk pools unaffordable and out of reach for many sick patients.[21] Several states have gone above and beyond others in covering high-risk patients by eliminating pre-existing condition exclusion periods. If health care reform includes a role for state high-risk pools, these states should be used as a model to further improve state high-risk pools so that high-risk individuals have access to health coverage and necessary care.

For cancer patients, health insurance discrimination is a serious, even life-threatening, practice. A 59-year old patient recently diagnosed with pancreatic cancer contacted PAF after

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[19] Families USA. Barebones Insurance Would Do Little to Help Uninsured Working Families. May 1999.
[20] Wu, S. Green, A. Projection of Chronic Illness Prevalence and Cost Inflation, RAND Corporation, October 2000.
[21] Chollet, Deborah. Expanding Individual Health Insurance Coverage: Are High-Risk Pools the Answer?. Health Affairs. October 2002.

her insurance denied her hospital claims of $100,000 stating her pancreatic cancer was a pre-existing condition. While the diagnosis was made during a visit to the Emergency Room for blood clots, there was no evidence in her medical records to substantiate the claim that the pancreatic cancer was a pre-existing condition that she had sough treatment for when she initially visited the Emergency Room. With the help of a PAF case manager, the insurance company eventually overruled their decision after multiple appeals by PAF and the patient.

While PAF is often successful with pre-existing condition discrimination cases, they are not always able to overturn a decision by an insurance company. Last year, PAF was contacted by a 64-year old man from Connecticut that had private coverage for many years with the same carrier; every six months the policy had to be renewed. In early January 2007, the patient had a lesion removed form his tongue but was advised that it was a soft tissue growth and not cancerous. Two days later he completed his renewal application and answered "no" when asked if he had been advised or diagnosed that he had cancer in the previous five years. The policy was renewed and was in effect until June when it was time for him to renew again, which he did. On July 20, 2007, the patient was advised that he had squamous cell carcinoma of the tongue. The patient was notified by his insurance policy a month later that his policy had been rescinded not only for the current plan but the immediate past policy as well citing that the patient had answered a question falsely. Unfortunately for this patient, the insurance company was within the current legal boundaries when they rescinded his policy. While the patient and PAF's Legal Resource Network are still seeking resolution, our current system allows these unfair practices to occur. The patient's insurance company was willing to collect his monthly premiums for years, until he was diagnosed with cancer and actually needed his health coverage.

National Patient Advocate Foundation understands that insurance companies need to protect themselves from risk, but at the same time, a responsible health care system doesn't exclude patients due to their health status. Reforms need to be implemented that protect insurers and employers from patients that are high-risk and have very high medical expenditures while at the same time, protecting patients and providing them with meaningful health benefits that cover necessary medical services.

Portable

Patients should be allowed to take their health coverage with them when they change jobs or move. National Patient Advocate Foundation is concerned that under our current system more and more Americans find themselves experiencing "job-lock", a phenomena that literally locks an individual in a particular job for fear of losing health coverage. Job-lock not only hurts patients, but it stymies innovation by reducing upward professional mobility across employer groups and it is not beneficial for the country's economy. Much has changed since health insurance was first introduced in the workforce in the early twentieth century; the average American worker will hold approximately 11 different jobs in their lifetime.[22] For most Americans, every change in employment brings a different health insurance policy with new benefits and network providers. Portable health insurance will allow for improved continuity of care and coordinated care because patients will not be forced to find new doctors that are part of their network every time they change jobs and health insurance policies.

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[22] U.S. Bureau of Labor Statistics National Longitudinal Survey Program, June 2008.

In the aftermath of Hurricane Katrina, Patient Advocate Foundation assisted many patients that had been displaced by the storm. Since many patients relocated to other states, they had difficulty locating their medical records and finding doctors that would treat them. For many, their care was interrupted and their health put at risk.

Patients routinely contact PAF with insurance problems related to the lack of portability that currently exists in our health care system. One patient, after being displaced by Hurricane Katrina, relocated to Texas temporarily. Unfortunately for this 47-year old lung cancer patient, her insurance was not accepted in Texas and thus could not access necessary treatment. Personal and natural disasters can force patients across state lines either permanently or temporarily. For patients with even minor health problems, these situations may result in them delaying care or accumulating medical debt if they cannot get their insurance to cover their care.

Patient Advocate Foundation successfully assisted another Katrina victim, a 71 year old man, who needed assistance finding a doctor for follow-up care for his hypertension when he was displaced by the storm. A responsible health care system promotes continuity of care for patients; however, this form of health care system requires health coverage that is truly portable.

Conclusion

National Patient Advocate Foundation is critically concerned about the broken state of our health care system and we are dedicated to our pursuit of reform to provide to this nation a responsible, universal, affordable, quality, fair & equitable and portable health care system. Discussion and implementation of health care reform must include public, private, nonprofit and government stakeholders. National Patient Advocate Foundation encourages stakeholders to work together to find consensus on principles that will form the foundation of health care reform policies and solutions. Patients, employers, providers, insurers, and elected officials know health care reform is needed now more than ever and the principles laid out in this paper address the broad issues and concerns NPAF seeks to remedy on behalf of the more than 27 million Americans who have sought direct health care information and or direct mediation from Patient Advocate Foundation since 1996.